Neonatal Intensive Care Unit Infants, Parental Stress, Couple and Family Impact: How Family Resources May Attenuate the Stress

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ABSTRACT

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The birth of a child is an exciting and challenging time for parents. The first few years following birth involve an adjustment period as parents work together to balance work, family, infant care, and self-care. Approximately 7 - 15% of parents will have an infant who will spend some amount of time in a Neonatal Intensive Care Unit (NICU). These parents experience the typical stressors associated with parenthood plus the additional stress of worrying about their infant's survival, development, and/or long-term health. After NICU discharge, parents are sent home to care for an ill and/or preterm infant and often continue to worry about rehospitalizations, ongoing health issues, and the long-term consequences of the experience. The impact of the NICU experience and subsequent infant health issues on parental and family outcomes is an understudied area that merits research attention.

The current study examined how the NICU experience and subsequent infant health problems that may follow during the first three years after discharge affects parental stress, couple functioning, and family dynamics. A variable known to attenuate stress and family outcomes (i.e., family resources) was included to study the contribution of this factor. Parents with infants who had been discharged from the NICU six months to three years ago were recruited via the Internet and posted flyers ($N = 199$). Parents reported objective indicators of their infants' health during the NICU admission and at

the present time, parenting stress, family burden, couple functioning, and access to family resources. Both parents were invited to participate to gain a more comprehensive picture of perspectives and experiences, and to compare responses of mothers and fathers. However, women (*n* = 182; 91.5%) greatly outnumbered men (*n* = 17; 8.5%) almost eleven to one in the sample making comparisons of mothers and fathers statistically underpowered. Multivariate regression analyses revealed that a shorter length of stay in the NICU, less infant rehospitalizations, and additional infant diagnoses following discharge were significant positive predictors of increased parental stress. Moreover, a higher number of medical devices used by the infant at discharge and fewer infant rehospitalizations were associated with poorer couple functioning. Infant use of extracorporeal membrane oxygenation (ECMO) during the NICU stay, a greater number of medical devices used by the infant during the NICU stay, the more specialists seen in the first year post-discharge, and the more medications currently prescribed, were all associated with greater family burden. Family resources did not significantly moderate (i.e., change or strengthen) the relationships between infant health and each outcome; however, fewer family resources was associated with increased parental stress, poorer couple functioning, and greater family burden. Analysis of covariance (ANCOVA) was used to examine sex differences and although no differences were found, analyses were greatly underpowered and should be interpreted with caution. Results suggest that infant health severity, the associated burden of care, and family resources are important contributors for parental and family adjustment. Family-focused interventions that incorporate information and skills on managing their child's health issues, communication between medical providers and parents, transitioning home from the

NICU, ways to adaptively coping strategies, and ways to overcome barriers to resources and treatment may be effective mechanisms to prevent negative psychosocial sequelae among NICU parents and families following discharge. Additional implications and future directions are discussed.

1. INTRODUCTION

The birth of a child is a challenging time for parents. Even when the child is healthy, the parents are in a loving and committed relationship and want and can afford the child, the child's birth is a eustressor (positive stress stimulus) that initiates a stress response. When the child is healthy, but the parents do not get along, do not want the child, or are not financially or psychologically prepared to raise the child, the combination of eustress (because of the healthy birth) and distress (because of the negative psychological and social milieu) creates a more stressful experience for the parents. The psychological toll of having a severely ill child can have serious negative effects on the parents, the child, and other members of the family. The extant research literature includes several studies of parents with infants who require neonatal intensive care unit (NICU) hospitalization and reveal psychological and behavioral issues for the parents (Lefkowitz, Baxt, & Evans, 2010; Obeidat, Bond, & Callister, 2009; Vigod, Villegas, Dennis, & Ross, 2010). These studies focus on the psychological reactions of mothers of preterm infants admitted to the NICU shortly after birth. Certainly, these reports provide valuable information, but the information is limited.

The present study built upon and extended these published works by examining the experience of mothers and fathers of infants who spent time in a NICU. The parents were surveyed several months to several years after NICU discharge, and included those whose infants were admitted to the NICU for any reason, including but not limited to preterm birth. The present study examined psychological responses to daily events; aspects of the parental relationship and family dynamic; whether family resources affect stress responses; and responses of mothers versus fathers.

Before presenting the details of the current study, an overview of contextual information about NICUs and parental experiences is provided, including information about NICUs in general; parental reactions to the NICU; parental stress at home; impact on the family; risk and resilience factors for stress and family burden; and sex differences relevant to the study. Next, the study's rationale, hypotheses, and methods are presented. The results, discussion, references, and supporting tables, figures, and documentation are then presented.

1.1 The Neonatal Intensive Care Unit (NICU)

A NICU is an intensive-care unit specializing in the medical care of ill or premature newborn infants. About 15% of newborns delivered each year are admitted to a special care nursery and about 58% of those admissions spend time in a NICU (March of Dimes Perinatal Data Center, 2011). Nearly half of all NICU admissions are preterm births, i.e., delivery occurring < 37 weeks gestation. Preterm rates have increased 13% from 1990 to 2010 because of a variety of factors, including advanced maternal age, early Cesarean deliveries, multiple births, and other complications during pregnancy (Committee on Fetus and Newborn, 2012). Other medical complications that can result in a NICU admission, include: respiratory distress syndrome, newborn septicemia, transitory tachypnea, infections, extreme immaturity, neonatal jaundice, neonatal hypoglycemia, prophylactic vaccination for viral hepatitis, and post-term birth (March of Dimes Perinatal Data Center, 2011). Most NICU admissions are singleton births and about 15% are multiples (March of Dimes Perinatal Data Center, 2011). The average length of stay for NICU admission is two weeks, but admission stays can range from 5 days to several months depending on the gestational age and medical complications of

the infant (March of Dimes Perinatal Data Center, 2011; Phillips-Pula, Pickler, McGrath, Brown, & Dusing, 2013).

While the number of infants admitted to NICUs is high, the survival rate for infants has increased over recent years because of significant advances in neonatal care (Committee on Fetus and Newborn, 2012). Health care researchers, public health officials, and organizations like March of Dimes have worked to improve the standards of care in NICUs. Currently, each NICU is equipped with the appropriate medical personnel, space, equipment, and technology necessary to provide for the infants (Committee on Fetus and Newborn, 2012). NICUs are classified by levels based on the care the infants need. Level I NICUs provide basic care and help stabilize and care for low risk infants born 35 - 37 weeks gestation or ill infants born less than 35 weeks. Level II NICUs provide specialty care for infants who are born 32 weeks or earlier and weigh < 1500 g at birth, but whose problems should resolve soon. Level III NICUs offer subspecialty intensive care and contain infants born < 1500 g or earlier than 32 weeks who have critical illnesses and may need to be sustained on life support. Level IV NICUs are similar to Level III, but also include surgical specialty consultants available 24 hours/day and include infants who are the most complex and critically ill (Committee on Fetus and Newborn, 2012). The condition of the infant and level of NICU can dramatically impact the parents' reactions and experiences. It is imperative to examine parents whose infants were in a variety of NICUs to more fully understand their perspectives and outcomes. The implications that the NICU experience has for parents and families needs to be better understood to help inform health care providers,

researchers, and clinicians how to best support and treat parents and families who have or have had an infant in the NICU.

1.2 Parental Reactions to the NICU

During infant hospitalization, parents may experience various forms of psychological distress. Parents often feel overwhelmed with mixed emotions, including feelings of stress, grief, anger, anxiety, happiness, relief, and confusion (Aagaard & Hall, 2008; Holditch-Davis, Miles, Weaver, Black, Beeber, & Thoyre, Engelke, 2009; Obeidat et al., 2009). For example, parents can experience complex and sometimes contradicting emotions because they are happy about the birth of their child, guilty about the pain and apparent discomfort of their child, disappointed that they did not have a healthy child, uncertain that they can properly care for their infant, and fearful about being a parent to a child with special needs. In addition, parents worry about their infant's survival, medical conditions of the postpartum mother and/or infant, and the transition to parenthood (Carter, Mulder, Bartram, & Darlow, 2007; Miles & Holditch-Davis, 1997). The NICU experience is best described as an emotional roller coaster "oscillating between hope and hopelessness" (Obeidat et al., 2009, pg. 26).

In addition to coping with overwhelming emotions, parents also find it difficult to carry out parenting activities in the critical care setting. Parents have reported that their leading source of stress in the NICU is their limited or uncertain parenting role (Busse, Stromgren, Thorngate, & Thomas, 2013). The postpartum period is a critical time for parents to bond with their infant. Yet, the unfamiliar and intimidating environment of the NICU can delay attachment (Heermann, Wilson, & Wilhelm, 2005). Parents of these newborns must quickly adapt to the NICU environment and its associated demands

including learning their way around the NICU while their infant is cared for by someone other than themselves, which may leave them feeling helpless (Phillips-Pula et al., 2013). Because parents typically lack the knowledge necessary to understand the medical jargon used to describe their babies' condition, feelings of frustration, confusion, and alienation can arise (Obeidat et al., 2009).

Although the range of emotions and experiences may be normative, they can have deleterious consequences for physical and mental health. Stress experienced by NICU parents is strongly correlated with anxiety, depression, fatigue, and sleep disturbance (Busse et al., 2013; Holditch-Davis et al., 2009). About 50% of mothers of premature infants have elevated levels of anxiety or depressive symptoms during their infant's hospitalization (Miles, Funk, & Kasper, 1992; Miles, Wilson, Docherty, 2000). Lefkowitz, Baxt, and Evans (2010) reported that 34% of mothers and 24% of fathers reported high levels of stress immediately following their NICU experience. One month later 15% of mothers and 8% of fathers met criteria for posttraumatic stress disorder. The unusual appearance of the infant and feelings of inadequacy, stress, guilt, and anxiety about the child's health can lead to adverse mental health outcomes for parents or inadequate parenting styles in the long-term (Boykova & Kenner, 2012). The elevated levels of stress and mental health symptoms can persist even after leaving the NICU. In fact, emotional stress may not subside over time. Parents are at risk for delayed stress responses making them a vulnerable population for future clinically significant symptoms (Lefkowitz et al., 2010; Shaw, Bernard, DeBlois, Ikuta, Ginzburg, & Koopman, 2009).

1.3 Parental Stress at Home

Taking care of a high-risk infant adds an extra burden to already stressed parents because they are suddenly responsible for an infant who needs a higher level of constant attention and care. Rather than planning for the future and celebrating the traditional development of milestones of their infant, parents focus on their infant's survival and worry about developmental delays or long-term effects of medical problems (Phillip-Pula et al., 2013; Schappin, Wijnroks, Venema, & Jongmans, 2013). Parents may continue to experience distress during the first few years following discharge because the care for these infants can be difficult and arduous (Howe, Sheu, Wang, & Hsu, 2014). In very low birth weight populations, parenting stress remains elevated for the first 18 months and does not become similar to stress reported by parents of full-term infants until the child is approximately two to three years of age (Treyvaud, 2014). Therefore, the first few years following NICU admission is a critical time to examine parents and families because of the high risk for stress and adverse psychological symptoms. Parental mental health outcomes following NICU stays also can have negative effects on the child's health and development (Treyvaud, 2014). Specifically, poorer psychological well-being (depressive symptoms and stress) of the mother, father, or both parents has been associated with more behavior and emotional problems as well as poorer language and cognitive development for the child (Huhtala, Korja, Lehtonen, Haataja, Lapinleimu, & Rautava, 2012; Treyvaud, 2014). Additionally, maternal posttraumatic reactions have been associated with sleeping problems for premature infants at 18 months whereas paternal posttraumatic reactions impact eating problems for the child (Pierrehumbert, Nicole, Muller-Nix, Forcada-Guex, & Ansermet, 2003).

The stress levels of parents may vary depending on the infant's health characteristics. Treyvaud (2014) stated that for parents of early preterm infants, higher parenting stress is associated with infant discharge home on oxygen, infant surgery for prematurity, lower birth weight, and higher neonatal risk. Further, the difference in stress levels between parents of preterm and term infants is influenced by the infant's birth weight: the greater the birth weight, the smaller the difference (Schappin et al., 2013). A probable mediator between preterm birth and parental stress is persisting child health problems (Taylor, Klein, Minich, & Hack, 2001). Therefore, it is vital to study parents of infants whose health ranges in severity and include parents of all infants admitted to the NICU. Past researchers have focused on preterm versus full term infants (Brummelte, Grunau, Synnes, Whitfield, & Petrie-Thomas, 2011; Gray et al., 2012; Howe et al., 2014). Including parents of NICU infants with a full range of diagnoses will provide more information regarding sources of parental stress and help to understand parental outcomes for all NICU infants.

Parenting stress is still significantly greater in parents of preterm infants compared to parents of full term infants when infants are one year of age (corrected age for preterms) (Grey et al., 2013; Brummelte et al., 2011; Davis, Edwards, Mohay, & Wollin, 2003). Singer, Salvator, Guo, Collin, Lilien, and Baley (1999) reported that at three years, parenting stress remained greater in mothers of high-risk very low birth weight (VLBW) children compared to mothers of term children. However, the source of parenting stress seems to change over time. During NICU admission, the parental role is a major source of stress as well as the severity of the child's medical condition. Immediately following NICU admission, the normal stressors of parenting,

rehospitalizations, and medical complications become a main source of stress. Within the first year, the direct influence of medical factors, such as illness severity, decline over time, whereas functional outcomes for the child (such as developmental delay) become more stressful for parents (Brummelte et al., 2011). To best understand parental stress, it is critical to examine the child's health at the time of NICU admission and at the present time. Based on the research, the potential outcomes for the child may be the most important determinant of parental stress levels. Past researchers have examined parental responses during or immediately following the NICU while few studies have examined the first few years following discharge (Carter et al., 2007; Lefkowitz et al., 2010; Obeidat et al., 2009; Shaw et al., 2009). The elevated psychological distress of NICU parents appears to continue over the early years of childhood with parents reporting less distress by the time the child reaches adolescence (Treyvaud, 2014).

In summary, the postpartum period and the elevated levels of stress associated with having an infant in the NICU place parents at increased risk to develop unfavorable psychological symptoms. Overall, parents of NICU infants have high rates of mental health problems in the early years of their child's life compared to parents of full-term healthy infants (Treyvaud, 2014). Specifically, NICU parents have exhibited symptoms of anxiety, depression, and posttraumatic stress disorder. One third of mothers with infants with very low birth weights had clinically meaningful levels of depression and anxiety (Singer et al., 1999).

1.4 Impact on the Family and Couple Relationship

Parents are not the only family members impacted by a NICU infant. In fact, siblings and other family members have to adjust to the challenges associated with the

transition from the NICU to home. After discharge, extremely low birth weight infants remain at increased risk for medical complications, rehospitalizations, and neurodevelopmental impairments (Lorenz, Wooliever, Jetton, & Paneth, 1998). The ongoing medical complications of the child can greatly impact the financial, social, occupational, and recreational aspects of family life (Stephens, Bann, Poole, & Vohr, 2008). In addition, the more dependent the child is on the caregiver, the more emotional impact the caregiver experiences (Stephens et al., 2008). Researchers suggest that a combination of medical and social/environmental risk factors negatively impact the family (Balakrishnan, Stephens, Burke, Yatchmink, Alksninis, Tucker, Cavanaugh, Collins, & Vohr 2011). Therefore, it is essential to examine the impact of a NICU infant on systems and dynamics within the family and the parents' intimate relationship.

Overall, poorer child health has been associated with poorer family functioning. Families with infants born at lower gestational ages, with lower birth weights, or at increased medical risk, report a more negative impact on the family (Treyvaud, 2014). Balakrishnan and colleagues (2011) reported that neonatal medical risk factors, longer hospitalization, more days on ventilator or oxygen, and lower gestational age were all associated with greater negative family impact. In addition, families with very preterm children reported poorer family functioning (assessed by the Family Assessment Device [FAD]; Epstein, Baldwin, & Bishop, 1983) and more family burden (assessed by the Impact on Family Scale [IOF]; Stein & Riessman, 1980) at two years from NICU discharge compared to families with term infants (Treyvaud, Doyle, Lee, Roberts, Cheong, Inder, & Anderson, 2011; Singer et al., 1999). Further, child impairment or disability can greatly impact the family environment. Neurodevelopmental disability or

developmental delay has been associated with increased negative impact of a NICU infant on the family and higher family burden (Saigal, Burros, Stoskopf, Rosenbaum, & Streiner, 2000; Singer et al., 1999; Treyvaud et al., 2011; O'Brien, Asay, & McClusky-Fawcett, 1999). Increasing severity of impairment in a NICU child has been associated with higher Impact on Family scores (IOF; Stein & Jessop, 2003), which reflects the general negative impact of the child on social and familial systems. In fact, in one study, severity of impairment explained 6% of the variance in impact on family scores (Stephens et al., 2008).

Parental characteristics also can influence the family environment. It is valuable to examine the influence that parental mental health has on the family because these parents are at increased risk of psychological distress, which in turn, affect family systems and parent-child attachment (Treyvaud et al., 2011). Specifically, maternal depressive symptoms have been associated with an increased perception of the child being a greater burden on the family (O'Brien et al., 1999). In addition, parental mental health and perceptions of attachments with the infant have been associated with adverse developmental outcomes for the child. Moreover, maternal postnatal posttraumatic stress disorder has been predictive of poorer infant cognitive development (Parfitt, Pike, & Ayers, 2014). Interestingly, maternal depression was related to the infant's language development, whereas paternal mental health was mainly linked to the couple's relationship and father-baby relationship (Parfitt et al., 2014). Maternal depression has also been linked to cognitive, behavioral, and emotional development issues in their children (Beck, 1999; Treyvaud, 2014).

Not only does parental mental health impact the family and child, but parental perception of the parents' relationship with their child can greatly impact the child's development. For example, the mother's perception of the mother-infant relationship has been associated with the child's language development, and the father's perception of his relationship with the infant was associated with the child's motor development (Parfitt et al., 2014). Child characteristics, parental characteristics, and parental perceptions of their relationship with their child can all impact the family dynamic, perceptions of family burden, and ultimately the child's development.

Another important variable that may be greatly impacted by the infant's health is couple functioning. For NICU families, transitioning to parenthood requires securing the infant's survival, caring for the infant, adjusting to daily life, and functioning as a family unit (Mosek-Eilon, Hirschberger, Kanat-Maymon, & Feldman, 2013). The transition can be difficult for parents of healthy as well as special needs infants, and maintaining a strong dyadic relationship is key to strong family functioning. Parents' of all newborns experience a greater decrease in marital satisfaction compared to non-parents (Doss, Rhoades, Stanley, & Markman, 2009). Saigal and colleagues (2000) reported that a significantly higher proportion of parents with extremely low birth weight children reported that their child's health status had caused stress and strain, brought the couple closer together, and was a major factor in separation in divorce. The impact that having a child admitted to a NICU has on a couple is somewhat mixed, however, few researchers have examined the parental relationship as an outcome that may be impacted by the NICU experience and subsequent infant health problems (Schappin et al., 2013).

Most research indicates that conflicts between the couple can negatively and indirectly impact the child's mental health by influencing the child's emotional security (Koss, George, Bergman, Cummings, Davies, & Cicchetti, 2011; Kouros, Cummings, & Davies, 2010). Treyvaud (2014) reported that across studies, lower marital satisfaction was related to poorer family and parental outcomes. In addition, the couple's relationship serves as a risk factor for adverse child outcomes (Hanington et al., 2012). Intriguingly, Parfitt and colleagues (2014) reported that the father's perception of the couple's relationship impacted the father-infant relationship. A better understanding of how the couple's relationship is impacted by a NICU infant could help inform researchers and clinicians on whether to address the couples' relationship in future interventions.

1.5 Risk and Resilience Factors for Stress, Couple and Family Impact

There are other imperative variables that can serve as risk or resilience factors for parental stress, family burden, and couple functioning in NICU families. Family resources, which include perceptions about financial status, social support, health care access, food, and shelter, play a critical role in the relationship between the child's health and parental stress, couple and family impact (Balakrishnan et al., 2011; Stephens et al., 2008). Family resources can be a great source of stress and strain and effect parental psychological distress and the family unit. Families who reported lower family resources (assessed by the Family Resources Scale [FRS]; Van Horn, Bellis, & Synder, 2001) reported greater overall stress and scored higher on the Impact on Family scale, indicating that they perceived the child as more of a burden to the family (Balakrishnan et al., 2011; Singer et al., 1999; Stephens et al., 2008). The more severe the child's illness, the more strain the child puts on family resources. Singer and colleagues (1999) reported

that at two years, mothers of high- and low- risk very low birth weight infants reported greater financial stress than mothers of term infants, but only mothers of high-risk infants reported greater family stress and higher overall stress. By three years, mothers of high-risk infants continued to report greater financial, family, personal, and total stress scores compared to mothers of full-term infants.

Some socio-demographic factors that may be pertinent to parental and family outcomes include socioeconomic status, education level, maternal age, number of children in the home, and amount of social support (Stephens et al., 2008, Treyvaud et al., 2011; Treyvaud, 2014). One factor that, to our understanding, has not been assessed is the reproductive history of the couple. Schappin and colleagues (2013) reported that they would expect parity or previous fertility treatment to impact parental stress. The combination of factors that impact parental and family outcomes for NICU families remains unclear and understanding the risk and resilience factors associated with parental stress and family burden may provide insight into the development and provision of targeted interventions to assist NICU families.

1.6 Sex Differences

The majority of research on parental outcomes for NICU families has focused on maternal self-report. Few studies have even included fathers and the ones that have were based on small sample sizes (Treyvaud, 2014). Overall, the research on sex differences is somewhat mixed. Most researchers have reported that mothers tend to report higher levels of psychological distress and parenting stress than fathers (Schappin et al., 2013; Treyvaud, 2014). Researchers suggest that this effect may be the result of gender roles rather than sex differences (Schappin et al., 2013). Specifically, the caregivers of the

families may experience more stress because they spend more time with the infant and deal with more medical issues. In contrast, other researchers have found less promising outcomes for fathers. Shaw and colleagues (2009) reported that four months after discharge, 33% of fathers met criteria for posttraumatic stress disorder, whereas 9% of mothers met criteria. Hynan (2005) reported that men and women do not differ in their psychological responses of having a child in the NICU. He suggests that mothers and fathers should be treated similarly. Interestingly, when it comes to perceptions of family functioning, no differences between mothers and fathers have been reported (Doering, Moser, & Dracup, 2000). Because most studies have focused on mothers, examining the stress and burden reported by fathers would provide a more comprehensive picture of the family and greater insight into the psychological well-being of NICU fathers in particular. High involvement in the family by fathers has been suggested to increase family cohesion, reduce maternal distress, and provide a buffer for infants if the mother is experiencing clinically significant mental health problems (Treyvaud, 2014).

The pattern of stress and the source of stress may differ for mothers and fathers. Studies that did investigate mothers and fathers found that fathers reported parental stress related to their marital status, parity of the infant, and temperament of the infant, while they did not report stress from delivery-related variables (Schappin et al., 2013). Mackley, Locke, Spear, & Joseph (2010) reported that for fathers, marital status and other life stressors were significant predictors of depression symptoms rather than child's illness severity. Fathers may experience high levels of stress because they have many physical and emotional responsibilities: they provide support to the mother and infant,

they worry about the infant's health, they communicate with friends and family, and in some cases they care for other children and continue working (Mackley et al., 2010).

In summary, to date, most research examining the NICU experience of parents focuses on mothers even though fathers' emotional needs are not being met. NICU fathers are an understudied population that requires more attention to determine the best interventions for parents and if they need to be tailored by sex or gender role (Schappin et al., 2013; Treyvaud, 2014). Understanding both parents experience and the other factors that are important can ultimately lead to successful interventions that will provide the support and treatment necessary to NICU parents to improve outcomes for their mental health and their families.

2. THE CURRENT STUDY

2.1 Rationale

Because of the high rate of infants admitted to NICUs (7 - 15%) and large number who continue to experience subsequent health problems, including retinopathy of prematurity, chronic neonatal lung disease, and periventricular/intraventricular hemorrhage, among many other medical issues (Gray et al., 2013), it is critical to understand the experience of NICU families in the first few years following discharge. The first few years of life are a time of tremendous growth and development for an infant. These medical issues can impair the infant's cognitive, behavioral, and social development, which can, in turn, negatively impact parental psychological well-being. Furthermore, the parental stress or psychological symptoms that stem from a child's impaired development can damage the parent-infant interaction. Specifically, high levels of parental stress and depression have been associated with more behavior problems,

poorer developmental social skills for children, and reduced interactive play between parent and child (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Forcada-Guex, Borghini, Pierrehumbert, Ansermet, & Muller-Nix, 2011; Huhtala et al., 2012). Most research focuses on the immediate effects of NICU admission for maternal psychological health, but the parental and family outcomes during this time remain understudied, as does the specific responses of fathers. In addition, understanding stress among parents is important for parental mental health. Examining stress in parents may provide a more complete understanding of which parents are at risk for unfavorable mental health outcomes. The outcomes represent parenting stress and family systems – parenting stress, couple functioning, and family burden. In the present study, family burden was defined as the perceived burden that an ill child has on the family. Each of these outcomes used the same predictors to compare and contrast which variables predicted these outcomes.

Family resources have been reported to impact parental stress and the family (Treyvaud et al., 2011; Treyvaud, 2014), although the research is limited. In the current study, family resources were defined as parental perception of adequate resources including basic needs, money, time for self, and time for family. Most research on NICU families has only examined preterm infants. Although most NICU admissions result from preterm births, we sought to extend the current literature by examining the experiences of all NICU families to determine how different infant health experiences impact parental and family outcomes. The current study was designed to understand how the severity of the NICU infant's health during hospitalization and at the present time is associated with parental stress, couple functioning, and family burden. In addition, the present study

examined how family resources moderate the relationship between infant health and parental stress, couple functioning, and family burden.

2.2. Hypotheses

Hypothesis 1:

(1) Parental report of infant health will explain a significant proportion of the variance in each dependent variable (parental stress levels, couple functioning and family burden) when controlling for time since discharge, number of children, and number of stressful life events.

(a) Parental report of more severe health indicators (e.g., birth weight; rehospitalizations; developmental disability) at the time of NICU admission and at the present time will be associated with:
(i) more parental stress,
(ii) poorer couple functioning, and
(iii) greater family burden.

Rationale for Hypothesis 1: It was hypothesized that parental report of their infant's health at the time of NICU admission and at the present time will influence perceptions of parenting stress, couple functioning and family burden. Specifically, the more severe the child's health problems at the time of NICU admission and at the present time, the more stress, family burden, and poorer couple functioning the parents will report. Indicators of infant health during NICU admission included gestational age, birth weight, length of time in NICU, number of medical devices used during the NICU stay (i.e., oxygen, ventilator, feeding tube, tracheostomy, phototherapy, Replogle Tube), use of extracorporeal membrane oxygenation (ECMO) during NICU stay, number of medical devices infant used at discharge (i.e., oxygen, ventilator, feeding tube, tracheostomy, cardiorespiratory monitor, ventral shunt, central line). ECMO is a heart-lung bypass machine used for some of the most medically critical infants in the NICU. Infant's current health was assessed by: number of medical devices infant is currently using (i.e., oxygen, ventilator, feeding tube, tracheostomy, cardiorespiratory monitor, ventral shunt,

central line, and nebulizer), presence of additional diagnoses and/or developmental disabilities, number of rehospitalizations first year post-discharge or since discharge (if discharged less than a year ago), number of medications infant is currently prescribed at the time of the survey, and number of specialists infant saw first year post-discharge or since discharge. Research suggests that parents with infants with increasing neonatal illness severity and born very preterm report greater parenting stress and family burden compared to parents with less severe infants (Balakrishnan et al., 2011; Treyvaud, 2014). Additionally, having an infant in a NICU has been associated with marital discord and more marital strain (Schappin et al., 2013; Treyvaud, 2014). Caring for a very preterm child with a neurodevelopmental disability increases the burden on family finances, planning, and parenting (Treyvaud et al., 2011). If this finding is confirmed, then families with more severe infants should be targeted for future early interventions. Balakrishnan and colleagues (2011) reported that social, environmental and medical risk factors contribute to family burden of very low birth weight infants, including number of children in the home, maternal perception of poorer family resources, lower gestational age, and chronic illness. Based on the extant literature, the variables we controlled for in each hypothesis included time since NICU discharge (months), number of children in the household, and number stressful life events that have occurred since the infant's birth. Identifying factors that contribute to the relationship between infant health and parental/family outcomes is key to supporting and treating families who have been discharged from the NICU.

Hypothesis 2:

(2) The relationship between infant health, parental stress, couple functioning, and family burden will be moderated by family resources when controlling for time since discharge, number of children, and number of stressful life events.
(a) Greater family resources will attenuate the resulting stress, couple and family impact.

Rationale for Hypothesis 2: A moderator affects the relationship between two variables, such that the impact of a predictor variable on an outcome variable changes according to the level of the moderator (Baron & Kenny, 1986). It was hypothesized that the parental report of more severe infant health indicators will negatively impact parental stress, couple and family impact. However, greater family resources will attenuate resulting stress, couple distress, and family burden. Family resources have been reported to buffer against parental stress and family burden. Moreover, dyadic adjustment is impacted by parental mental health. In fact, mothers with greater social support and less stress during pregnancy experienced less decline in family and marital functioning (Ngai & Ngu, 2014). Moreover, families with fewer resources are particularly vulnerable to greater family burden (Stephens et al., 2008). This factor may moderate the relationship between infant health severity and parental and family outcomes. To our knowledge, no study has investigated this factor as a moderator. Furthermore, as addressed above we controlled for variables known to impact this relationship (i.e., time since NICU discharge, number of children in the home, and number of stressful life events since infant's birth).

Hypothesis 3:

(3) Men and women will differ across all dependent variables (parental stress, couple functioning, and family burden) when controlling for number of children, time since discharge, and number of stressful life events.
(a) Women will report more parental stress, poorer couple functioning, and greater family burden than men.

Rationale for Hypothesis 3: It was hypothesized that men and women will differ across the three dependent variables (i.e., parental stress, couple functioning, and family burden). Most researchers report that mothers tend to exhibit more psychological distress than fathers (Treyvaud, 2014). Moreover, Stephens and colleagues (2008) reported that the more severe the child's illness, the more emotional impact the caregiver experiences. Because mothers tend to be the primary caregiver, we hypothesized that women would experience more stress, couple distress, and family burden than men. In addition, mothers who have experienced a complicated pregnancy, labor, or delivery, may be struggling with feelings of inadequacy as a mother and with bonding with her child (Schappin et al., 2013). Therefore, women may report more parenting stress due to any delivery-related variables. Overall, due to the lack of studies that include fathers, the research literature is somewhat mixed regarding sex differences. Hynan (2005) reported that mothers and fathers have similar stress responses; however, mothers and fathers tend to be influenced by different factors. Specifically, father's perception of their neonates is less influenced by the infant's medical condition compared to the mother (Ahn & Kim, 2007). Yet, Doucette and Pinelli (2004) reported that 18 to 24 months after NICU discharge, mothers reported improved family functioning whereas fathers reported worse family functioning. Moreover, infant health appears to be a factor that influences maternal and paternal stress differently because the sources that cause stress differ for mothers and fathers (Schappin et al., 2013). Because of the lack of research on fathers, mothers and their male partners will be included in order to understand their specific or similar experiences. Ultimately, these findings could inform researchers, clinicians, and health care providers of specific actions to support and treat both parents of NICU infants.

3. METHODS

3.1 Overview

The present study examined how parental report of infant's health (severity assessed by health indicators at the time of NICU admission and at the present time) impacts stress levels and couple and family adjustment for parents with infants who are six months to three years post-NICU stay. Family resources were assessed as a moderating variable and sex differences were examined. The study utilized an online cross-sectional self-report survey design. Participants were recruited on social media websites and through posted flyers. Preliminary analyses were conducted to assess descriptive statistics of socio-demographic variables, infant health characteristics, and quantitative self-report measures. Additionally, initial relationships were examined between key variables through bivariate correlations. Bivariate correlations, multivariate regression, moderation analyses, and analyses of covariance (ANCOVA) were conducted to examine planned hypotheses and exploratory analyses. Details on participants, design, procedures, and analyses are provided below.

3.2 Participants

3.2.1 Inclusion Criteria

Eligible participants were biological mothers of infants who were admitted to a NICU and their partners or spouses. The infant and family were discharged between six months to three years ago, and the mothers and partners were currently in an intimate relationship with each other and cohabitating together and with the infant since NICU discharge. Participants were at least 18 years old at the time of entry into the study and resided in the United States. The infant was currently alive and must have been born a

singleton. Participants understood written English and had access to the Internet. Eligibility was determined by self-report through screening questions and demographic information (i.e., years in a relationship, infant date of birth, infant current health status). Participants agreed to participate and gave waiver of consent (see Appendix A).

3.2.2 Exclusion Criteria

Individuals who had an infant in the NICU, but had not lived with their partner and/or infant since NICU discharge were not eligible for participation. Individual's whose infant was discharged less than six months ago or whose infant is no longer living were not eligible to participate in the study. We only included families in the analyses who had a singleton infant in the NICU to keep families consistent. Families who had multiple infants may experience increased stress because of the number of children in the home of the same age, or the possibility that one or more of the multiples could have passed away.

3.2.3 Recruitment and Participant Flow

Participants for the current study were recruited using the Internet and posted flyers. One hundred ninety nine NICU parents were recruited, which exceeds the necessary sample size identified through the power analyses detailed below in the Power Analyses section. Four hundred four participants started the survey; however, 136 were deemed ineligible based on the study's inclusion criteria. Sixty-nine participants were dropped because of missing data. See Figure 1 for participant flow information.

The study was advertised through flyers and on online support communities and social networking websites (e.g., Facebook, Craigslist, YouTube) with information related to parenting and a link to the online Qualtrics survey. Flyers were posted at

Drexel University and the Mother-Baby Connections Program outpatient clinic on Drexel's Center City campus. Flyers were also passed out at relevant conferences and were available at the Children Hospital of Philadelphia's developmental follow-up clinic for NICU graduate families. Specifically for online recruitment, researchers posted on Craigslist weekly in cities all over the United States. Researchers created a Facebook page that was kept active weekly by sharing parents' NICU journeys, articles, or interesting posts. Additionally, NICU parent support groups were contacted privately through Facebook messages with a request to advertise about the study and to post a link to the survey. Interested participants accessed the study through the link provided on the flyer or through the recruitment ad. Recruitment has been ongoing since August 2015. Once the study is closed, the research team plans to donate $1 per participant to the National Perinatal Association to thank participants for sharing their experiences, and to benefit pregnant women, infants, and families. The recruitment advertisement stated that at least 150 participants were expected to participate (see Appendix A).

3.3 Data Collection and Procedure

Participants were recruited using the methods described above. The recruitment advertisement and flyer provided participants with a brief description of the study, the inclusion and exclusion criteria, and the link to the online Qualtrics survey (see Appendix A). The link directed them to a webpage containing the waiver of consent, which included a detailed description of the eligibility criteria, the study purpose, procedure, risks and benefits, confidentiality, and the fact that their participation is voluntary. After reading through the waiver of consent, parents who self-identified as meeting eligibility criteria and agreed to participate were directed to the measures for the study. The first

page of the survey consisted of socio-demographic questions, including screening questions for inclusion and exclusion criteria. Only parents who met the inclusion and exclusion criteria had the opportunity to complete the remainder of the study measures. Parents who did not meet criteria for study participation were directed to a page at the end of the survey and thanked for their time.

3.4 Ethical Considerations

Because of the sensitive nature of the study, ethical concerns were considered and addressed when developing the current study. First, parents were informed that participation is entirely voluntary and that they could withdraw from the study at any time. Second, parents were assured of anonymity and confidentiality, no identifying information was collected and all responses were anonymous. Both concerns were clearly addressed in the waiver of consent. Because the topic matter of their child's health potentially could cause participants to experience psychological distress, participants were provided with contact information for the principal investigator and the Drexel University Office of Regulatory Research Compliance (see Appendix A). In addition, the flyer and waiver of consent encouraged participants to contact the principal investigator or research coordinator with any questions or concerns (see Appendix A). A referral list appeared at the end of the survey with resources for support groups for NICU parents (see Appendix C).

3.5 Measures

Copies of all measures are included in Appendix B. The entire survey took participants approximately 20 - 40 minutes to complete, which is consistent with previously published administration times and pilot testing for each measure.

3.5.1 Socio-Demographics Questionnaire

A socio-demographics questionnaire (see Appendix B) created for this study was used to collect information regarding participants' sex, age, race/ethnicity, religious identity, education level, household annual income, employment status, couple or relationship status, infant's sex, reproductive history, mental health history, and stressful life events that have occurred since infant's birth. The life event questions were adapted from Sarason, Johnson, and Siegel (1978) Life Experiences Survey, such that only relevant major negative life events were included (i.e., death, health issues/injuries, financial issues and job loss, and legal trouble).

3.5.2 Infant Past and Current Health

A questionnaire created for this study was used to measure infant's health (see Appendix B) during NICU admission and at the present time. The questionnaire collected information through parental report of infant health indicators including infant diagnosis/diagnoses, birth weight, gestational age, length of time in NICU, medical devices that the infant used during NICU stay (i.e., oxygen, ventilator, feeding tube, tracheostomy, phototherapy, or Replogle Tube), whether infant was on ECMO during NICU hospitalization, medical devices used post-discharge (i.e., oxygen, cardiorespiratory monitor, feeding tube, tracheostomy, ventricular shunt, central line). In addition, infant's health at the present time was measured by asking parents to identify any additional infant diagnosis/diagnoses, developmental disabilities, medical devices the infant is currently on (i.e., oxygen, cardiorespiratory monitor, feeding tube, tracheostomy, ventricular shunt, central line, nebulizer), number of rehospitalizations in first year post-discharge (or since discharge for infants discharged less than 1 year ago), number of

specialists' infant saw first year post-discharge or since discharge, and number of medications infant is prescribed at the time of the survey (and which ones). Items were either used as descriptive data and/or were entered in the analyses as separate predictors to determine how each impacted parental and family outcomes. Balakrishnan and colleagues (2011) used a similar system when examining parental report of infant health because the only current measures of infant health severity require information from medical staff or the hospital (Dorling, Field, & Manktelow, 2005). Balakrishnan and colleagues (2011) reported that the specific indicators of infant health severity most important for family burden included: discharge on oxygen or monitor, lower gestational age, longer hospitalization, number of days on oxygen or ventilator, presence of chronic lung disease, and requirement of pulmonary medications. We hoped to replicate and extend these findings by examining more items that may be related to parental and family outcomes as well as understand more information about the range of health issues that may require significant care and attention and therefore are difficult to manage.

The health indicators selected for this study were based on variables utilized in extant literature, consultations with NICU developmental psychologists and a neonatologist at the Children's Hospital of Philadelphia (CHOP), and a published review of the current knowledge regarding neurodevelopmental outcomes of preterm births (Nosarti, Murray, & Hack, 2010). Although measures that assess infant health severity exist, the current scoring systems require medical and physiological information that only medical staff can report. At the present time, there is no such measure for parental report (Dorling, Field, Manktelow, 2005). The objective indicators of infant health included in this measure were selected to help minimize the subjective bias of parental report.

3.5.3 Parental Stress Index, Short Form

The Parenting Stress Index, Short Form (PSI – SF; Abidin, 1995) is a 36-item self-report measure of stress directly associated with the parenting role (see Appendix B). Participants used a 5-point Likert scale to indicate the degree to which they agree with each statement, with higher scores indicating higher parental stress. Haskett, Ahern, Ward, & Allaire (2006) reported that the PSI– SF includes three subscales: parental distress, parent-child dysfunction interaction, and difficult child. The parental distress subscale yields a score that indicates level of distress resulting from personal factors such as depression, conflict with a partner, and life restrictions due to the demands of having a child (Haskett et al., 2006). The parent-child dysfunctional interaction subscale refers to parents' dissatisfaction with attachment/interactions with their child and how the child meets their expectations. The difficult child subscale measures parents' perceptions of their child's self-regulatory or behavioral abilities that make him/her difficult to manage. Subscale scores consist of 12 items each and range from 12 to 60, whereas the total score ranges from 36 to 180. Scores greater than or equal to 90 are considered clinically significant (Haskett et al., 2006).

The PSI – SF is one of the most common tools for assessing parents' levels of stress, has been used in mothers of preterm infants, and has strong reliability and validity (Haskett et al., 2006; Gray et al., 2013). Specifically, the internal consistency for the parental distress subscale (Cronbach's $\alpha = .88$), parent-child dysfunctional interaction subscale (Cronbach's $\alpha = .88$), difficult child subscale (Cronbach's $\alpha = .89$), and overall stress (Cronbach's $\alpha = .95$) were acceptable. In addition, criterion validity and discriminant validity were satisfied (Reitman, Currier, Stickle, 2002). The subscales were

correlated with measures of parent psychopathology (r = .54), parental perceptions of child behavior adjustment (r = .61), and observed parent (r = .23) and child (r = -.25) (Haskett et al., 2006). In addition, concurrent validity was achieved. For the difficult child subscale, child opposition and level of maternal symptomology and income accounted for 40% of the variance in this subscale. Self-reported psychological symptoms, family income, and maternal education contributed to 22% of the variance in the parent-child dysfunction interaction subscale. Finally, maternal psychological symptoms and family income accounted for 17% of the variance in the parental distress subscale (Reitman et al., 2002). PSI-SF scores were related to parents' report of their child's disruptive behavior in the home one-year later, demonstrating adequate predictive validity (Haskett et al., 2006).

3.5.4 Impact on Family Scale Revised

The Impact on Family Scale Revised (IOF – R; Stein & Jessop, 2003) is a 15-item self-report measure that assesses the perceived burden that an ill child has on the family (see Appendix B). The measure reflects parent perception of changes in family life and attribution of those changes to the child's illness. An example item includes: "Our family gives up things because of my child's illness." Participants respond on 4-point Likert scale of agreement (1 = *strongly agree* to 4 = *strong disagree*), with higher scores indicating higher degree of burden on the family because the items are reverse coded. The total score ranges from a minimum of 15 to a maximum of 60, with the total score being calculated by summing items.

The revised IOF total score is highly correlated with the original total score (r = .97) (Stein & Jessop, 2003). Internal consistency for the IOF was adequate (Cronbach's α

= .85) and construct validity was solid. In fact, the construct validity reinforces the usefulness and sensitivity of this measure because higher IOF scores were significantly associated with maternal psychiatric symptoms (r = .47), poor health for child (r = -.39), and poorer psychological adjustment for child (r = -.37) (Stein & Jessop, 2003).

3.5.5 Revised Dyadic Adjustment Scale

The Revised Dyadic Adjustment Scale (RDAS; Busby, Christensen, Crane, & Larson, 1995) is a 14-item self-report measure that assesses quality of relationships for married or unmarried cohabitating couples (see Appendix B). Participants respond on a 6-point Likert scale of agreement (0 = *always disagree* to 5 = *always agree*), with lower scores indicating greater distress and discord in the dyad (Gray et al., 2012). Three factors of the RSAD have been reported: dyadic consensus, dyadic satisfaction, and dyadic cohesion (Busby et al., 1995).

Busby and colleagues (1995) reported adequate reliability and validity. Internal consistency for all subscales and overall RDAS were acceptable (RDAS Cronbach's α = .90, consensus subscale Cronbach's α = .81, satisfaction subscale Cronbach's α = .85, and cohesion subscale Cronbach's α = .80). Split-half reliability was strong (RDAS Guttman split-half = .94, consensus subscale Guttman split-half = .88, satisfaction subscale Guttman split-half = .88, and cohesion subscale Guttman split-half = .79). The RDAS has less than half the items as the Dyadic Adjustment Scale (DAS) and was as successful at discriminating between distress and non-distressed individuals indicating adequate discriminant validity. In addition, the RDAS was correlated with another popular marital measure (Locke-Wallace Marital Adjustment Test [MAT; Crane, Allgood, Larson, & Griffin, 1990]), demonstrating solid construct validity (r = .68) (Busby et al., 1995).

3.5.6 Family Resource Scale, Revised

The Family Resource Scale, Revised (FRS – R; Van Horn, Bellis, & Synder, 2001) is a 20-item self-report measure that assesses the perception of adequate resources needed for family members and family as a whole (see Appendix B). Participants respond on a 5-point Likert scale of adequacy (1 = *not at all adequate* to 5 = *almost always adequate* or 0 = *does not apply*), with higher scores representing perceived access to more resources. Factor analyses revealed four distinct subscales: basic needs, money, time for self, and time for family (Van Horn et al., 2001). The FRS – R items ask parents' about their perceived availability of resources such as food, shelter, transportation, financial resources, healthcare, and social support (Balakrishnan et al., 2011; Stephens et al., 2008).

The measure demonstrates adequate internal consistency for each subscale: basic needs, Cronbach's $\alpha = .72$; money, Cronbach's $\alpha = .81$; time for self, Cronbach's $\alpha = .79$; and time for family, Cronbach's $\alpha = .76$ (Van Horn et al., 2001). Percent of poverty, respondent's education, and respondent's job status account for 1.5% of variance in time for self, 5.7% in basic needs, 6.2% in time for family, and 23% in money, demonstrating good convergent validity (Van Horn et al., 2001). Compared to other family resources variables, the FRS – R predicted more meaningful variance (6.4%) in the Social Skills Rating System (SSRS), which assesses child cognitive and behavioral outcomes suggesting good predictive and external validity (Van Horn et al., 2001).

3.6 Power Analyses

Using the program G*Power 3.1.7 (Faul, Erdfelder, Lang, & Buchner, 2007; Faul, Erdfelder, Buchner, & Lang, 2009) and past literature the sample size for the current

study was determined. Prior literature utilizing similar variables ranges from small to medium effect sizes. However, the studies that reported small effect sizes examined parental outcomes for preterm compared to full-term infants and researchers suggested that the small effect may be due to the relatively healthy samples of preterm infants that were included (Schappin et al., 2013). Additionally, sample sizes around 100 - 150 are typical for this population in assessing similar outcomes (Balakrishnan et al., 2011; Brummelte et al., 2010; Doucette et al., 2004; Taylor et al., 2001; Treyvaud et al., 2011). Therefore, because of the variety of infant diagnoses and health issues we included, the strong impact that infant health severity has on parental and family outcomes, and the sample sizes in prior studies, medium effect sizes were selected.

For Hypothesis 1, hierarchical regression analyses were used to examine how parental report of infant health indicators at the time of NICU admission and at the present time impacts parental stress, couple functioning, and family burden. To be conservative, we estimated that each regression would include ten predictors of infant health and three covariates. Therefore, 118 participants were needed in order to produce a power of .80 with a medium effect size (.15) if alpha is set at .05.

For Hypothesis 2, 127 participants are needed to achieve a power of .80 with a medium effect size (.25) and alpha set at .05. Regression analyses were run to test moderation (i.e., top five infant health indicators were estimated to be predictors, family resources as a moderator, and the three covariates [time since NICU discharge, number of children in home, and stressful life events]). Regression analyses were run for each outcome measure. Separate moderation analyses were run with each predictor being

significant indicators of infant health (based on regression and outcome) and the moderator being family resources for each outcome in PROCESS (Hayes, 2013).

For Hypothesis 3, sex differences were examined using analysis of covariance (ANCOVA). To achieve power of .80 with a medium effect size (.25) and alpha of .05, 128 participants were needed. The covariates included number of times since NICU discharge (months), number of children in household, and number of stressful life events.

Because the study was based on online responses, it was reasonable to assume that 128 participants could be recruited. According to the United States Census Bureau, in 2011 about 72% of household have access to the Internet (Computer and Internet Use in the United States, 2013). In addition, about 7 - 15% of the newborn births delivered annually in the United States are admitted to a NICU (March of Dimes Perinatal Data Center, 2011; Schwartz, Kellogg, & Muri, 2000). Therefore, because of the high prevalence of NICU births and households that have access to the Internet, it was reasonable to assume that we could recruit enough participants. Based on the results of power analysis and potential for attrition (incomplete surveys), the largest sample size needed was increased by 30%, so the initial recruitment goal was 167 individual participants from NICU families.

4. RESULTS

Data were analyzed using SPSS 22.0 statistical package. Initial descriptive analyses were conducted to examine the characteristics of the participants and to examine primary variables. Statistical analyses, as described below, were conducted to evaluate planned hypotheses. Assumptions of all proposed statistical analyses were examined prior to statistical examination and were met. For the purposes of statistical evaluation,

complete datasets were defined as those in which the participant answered every question for the outcome measures relevant to the particular hypothesis being evaluated.

4.1 Participant and Infant Characteristics

4.1.1 Participant Socio-Demographics

Descriptive statistics for all socio-demographics of the sample were examined (see Table 1). Of the 199 eligible participants who completed the survey, a majority was female (*n* = 182; 91.5%) and identified as non-Hispanic White (*n* = 163; 81.9%). The remaining participants identified as African-American (*n* = 13; 6.5%), Latina/Latino/Hispanic (*n* = 8; 4.0%), Bi/multiracial/ethnic (*n* = 7; 3.1%), Asian/Pacific Islander (*n* = 4; 2.0%), and Other (*n* = 3; 1.5%) with one participant declining to provide their race/ethnicity. The mean age of participants was 31.75 years old with a standard deviation of 5.34 and a range of 18 - 50 years old. Most participants identified as Christian (includes all forms of Christianity that do not identify with Catholicism) (*n* = 104; 52.3%).

All participants reported that they were in an intimate relationship with their partner and most participants were married (*n* = 169; 84.9%). The average length of time participants had been with their partner was 8.25 years with a standard deviation of 4.23 and a range of 1 - 23 years. There was a range in terms of estimated annual household income and educational attainment across participants, with the greatest percentage earning $25,000-74,999 (*n* = 91; 45.70%) and having achieved up to, but not past, a Bachelor's (four year college) degree (*n* = 67; 33.70%). Regarding employment status, the plurality of participants reported full-time employment status (*n* = 74; 37.2%) or being stay at home parents (*n* = 74; 37.2%). A majority of the participants did not report

being the sole caregiver of the child (*n* = 145; 72.9%). Male and female socio-demographics are reported in Table 1.

4.1.2 Participant Reproductive and NICU History

See Table 2 for detailed information about participants' reproductive and NICU history. One hundred fifty four participants (77.3%) reported that they had either one or two children, with the greatest percentage of participants reporting that this was their first baby (*n* = 95; 47.7%). In terms of prior reproductive history, 35.4% (*n* = 70) indicated that they had experienced a pregnancy loss in the past, ranging from 1 - 11 prior losses. Of these participants, 57.1% (*n* = 40) experienced one loss, with another 20% (*n* = 14) having experienced two losses. Twenty-two participants (11.1%) had used fertility treatments in the past, and fifteen of those (68.2%) had used fertility treatments to conceive the baby that was admitted to a NICU. Of the 199 participants, 60.3% (*n* = 120) reported that were aware that their child was going to be admitted to the NICU prior to admission. Most participants reported that they and/or their partner were not currently pregnant (*n* = 187; 94%).

4.1.3 Infant Health Characteristics

Indicators of infant health severity varied across the sample (see Tables 3, 4, 5, 6). The mean gestational age at birth was 31.54 weeks with a standard deviation of 4.64 and the mean birth weight was 1791.54 grams with a standard deviation of 1000.82. On average, infants were in the NICU for 7.63 weeks with a standard deviation of 6.30. The mean time since discharge was 1.28 years with a standard deviation of .86 years. See Table 3.

During the NICU stay, 67 infants were on oxygen, ventilator, and a feeding tube (33.6%) and almost all infants were on some combination of these three devices (see Table 4). In addition, most infants were not on ECMO (*n* = 185; 97%), while eight infants were on ECMO (4%). A majority of infants were discharged without any medical devices (*n* = 133; 66.8%). For infants discharged on a medical device, cardiorespiratory monitor was the most common (*n* = 20; 10.0%). Moreover, most infants were not prescribed any medical devices currently (*n* = 176; 88.4%). For infants currently using medical devices, feeding tube was the most common (*n* = 9; 4.5%). See Table 4 for more information about medical devices and ECMO.

Common diagnoses for infants during NICU admission included reflux (*n* = 65; 32.7%), apnea (*n* = 62; 31.2%), respiratory distress syndrome (*n* = 55; 27.9%), and chronic lung disease (n = 39; 19.6%). For information on diagnoses, please see Table 5.

Fifty-four infants were diagnosed with an additional condition after NICU discharge (27.4%) and 47 were diagnosed with a developmental disability (23.6%). Of the 47 infants with additional diagnoses, 21 of them were diagnosed with a developmental disability (39.6%). Most infants were not rehospitalized following NICU discharge (*n* = 146; 73.4%) and were not currently prescribed medication at the time of the survey (*n* = 138; 69.3%). However, most infants saw at least one additional specialist, other than the pediatrician, during the first year following discharge. Infant current health characteristics are displayed in Table 6.

4.2 Preliminary Analyses

4.2.1 Descriptive Statistics on Primary Variables

Descriptive statistics for all quantitative self-report outcome measures were analyzed and reported (see Table 7). The primary variables of interest included parental stress, couple functioning, family burden, and family resources.

The mean for parental stress, as measured by PSI-SF was 73.72, with a standard deviation of 22.14 and a range of 36 - 156. Higher scores indicate higher levels of parental stress, and a score of 90 or above on the PSI-SF indicate clinically significant parenting stress. Skewness was determined to be .847, with a standard error or .181, indicating a significant positive skewed distribution, $p < .001$. A positively skewed distribution indicates that scores on this measure tended to cluster further to the left on the distribution than expected in a normally distributed sample, suggesting that many women who participated in this study generally had stress scores that clustered below the average of a normally distributed sample. However, based on the size of the sample, the significant positive skew is not of concern, because larger sample sizes tend to produce small standard errors that result in significant skewness even for minor deviations from normality (Field, 2005). In fact, 37 participants (20.44%) had a score of 90 or higher, indicating concern for severe parental stress in the current sample.

The mean for couple functioning, as measured by Revised Dyadic Adjustment Scale (RDAS) was 46.56, with a standard deviation of 8.97 and a range of 14 - 65. Lower scores indicated greater distress and discord in the dyad functioning, and a score of 48 on the RDAS distinguishes between distressed and non-distressed couples. Skewness was determined to be -.869, with a standard error or .174, indicating a significantly negatively skewed distribution based on tests of normality, $p < .001$. A negatively skewed

distribution indicates that scores on this measure tended to fall further to the right on the distribution than expected in a normally distributed sample, suggesting that a majority of parents who participated in this study generally reported better than average couple functioning. Eighty-five participants (43.36%) had a score of 47 or below, indicating marital/relationship distress.

The mean for family burden, as measured by IOF-R was 16.31, with a standard deviation of 17.25 and a range of 0 - 59. Higher scores indicated more perceived family burden because of the child's illness. Skewness was determined to be .787, with a standard error of .179, indicating a significantly positively skewed distribution based on tests of normality, $p < .001$. A positively skewed distribution indicates that scores on this measure tended to fall further to the left on the distribution than expected in a normally distributed sample, suggesting that a majority of parents who participated in this study generally reported less family burden than the average of a normally distributed sample.

The mean for family resources, as measured by FRS-R was 80.10, with a standard deviation of 17.10 and a range of 3 - 105. Higher scores indicated more perceived family resources (i.e., basic needs, money, time for self, time for family). Skewness was determined to be -1.332, with a standard error of .179, indicating a significantly negatively skewed distribution based on tests of normality, $p < .001$. A negatively skewed distribution indicates that scores on this measure tended to fall further to the right on the distribution than expected in a normally distributed sample, suggesting that a majority of participants reported having more family resources than would be expected on a normal distribution.

4.1.2 Bivariate correlations

Pearson product-moment correlation coefficients between primary and continuous variables were computed to determine initial relationships (see Table 8). Correlations between the following variables were examined: specific indicators of infant health (i.e., gestational age, birth weight, length of time in NICU, number of medical devices [during NICU, at discharge, and currently], number of rehospitalizations, number of specialists seen during first year post-discharge or since discharge, number of current medications prescribed at the time of the survey), PSI – SF total score, RDAS total score, IOF – R score, and FRS score (see Table 8). Most infant health indicators were significantly correlated with one another. However, number of medical devices currently in use was not associated with number of medical devices used during NICU admission. Moreover, number of rehospitalizations during the first-year post discharge (or since discharge, if less than a year since discharge) was not associated with birth weight during NICU admission or number of medical devices infant was on during their NICU stay. Of interest, parenting stress was positively correlated with number of medical devices infant used during NICU stay ($r = .156$, $p < .05$); number of medical devices at discharge ($r = .285$; $p < .001$); number of medical devices currently in use ($r = .256$, $p < .01$); and number of specialists infant saw during first-year post discharge or since discharge (if less than a year) ($r = .245$, $p < .01$). Dyadic adjustment was negatively correlated with number of medical devices at discharge ($r = -.215$, $p < .01$) and parental stress ($r = -.485$, $p < .001$). Family resources was negatively associated with parental stress ($r = -.396$, $p < .001$) and positively associated with dyadic adjustment ($r = .406$, $p < .001$). Notably, impact on family was significantly associated with all variables in the table (see Table 8).

In sum, higher parental stress was associated with a greater number of medical devices during NICU, at discharge, and at the present time, more specialists, and fewer family resources. Poorer dyadic adjustment was associated with more medical devices at discharge and fewer family resources. Greater family burden was associated with increasing infant health severity (all indicators) and fewer family resources.

4.2 Main Analyses

4.2.1 Hypothesis 1

The first hypothesis stated that parental report of infant health indicators during NICU admission and at the present time would be associated with more parental stress, couple distress, and family burden. For Hypothesis 1, hierarchical regression analysis was used to examine how the severity of the infant's health indicators impacted parental and family outcomes (i.e., parenting stress, couple functioning, and family burden). Separate regressions were run for each outcome variable. Most of the predictors were coded continuously (i.e., gestational age; birth weight; length of time in NICU; number of medical devices infant used during NICU stay; number of medical devices used at discharge; number rehospitalizations in first year post-discharge; number of specialists seen in first year or since discharge; number of medications currently prescribed at time of the survey). A few dichotomous variables were dummy coded (i.e., whether infant was on ECMO during NICU stay; presence of developmental disability; additional diagnoses after discharge). Each regression included time since NICU discharge, number of children in the household, and number of stressful life events since infant's birth as covariates. These covariates were entered into block one of the hierarchical regression as a way of controlling for them in the analysis. The predictors were entered into block two

of the regression. Multicollinearity diagnostics indicated that gestational age and birth weight were highly correlated ($r = .827$, $p < .001$) and therefore if they were both included in the model, then they would account for less variance together. Birth weight was chosen to be in the model based on previous literature as opposed to, gestational age, which was not included. Additionally, analyses indicated that the covariates (i.e., time since discharge, number of children, and number of stressful life events) did not all explain a significant portion of the variance in each outcome. However, these variables were still included in each model as covariates given their theoretically important contribution to the outcomes (see Tables 9, 10, 11).

A hierarchical regression indicated that the overall model for infant health severity predicting parental stress when controlling for number of children, time since discharge, and number of stressful life events since the child's birth was significant, $F(14, 154) = 3.990$, $p < .001$, $R^2 = 26.6\%$. Infant length of stay in the NICU, presence of additional diagnoses following discharge, and number of rehospitalizations since discharge were significant predictors of parental stress (see Table 9). Specifically, parents of infants who were diagnosed with an additional condition following discharge reported more parenting stress compared to parents of infants who were not. Surprisingly, a longer length of stay in the NICU and a higher number of infant rehospitalizations following discharge were associated with less parental stress.

A hierarchical regression indicated that the overall model for infant health severity predicting couple functioning when controlling for number of children, time since discharge, and number of stressful life events since the child's birth was significant, $F(14, 169) = 2.566$, $p < .01$, $R^2 = 17.5\%$. Number of medical devices the infant needed at

discharge and number of rehospitalizations were significant predictors of couple functioning (see Table 10). Specifically, the fewer medical devices the infant had at discharge was associated with better couple functioning (less relationship distress). Surprisingly, a higher number of infant rehospitalizations was associated with better couple functioning.

A hierarchical regression indicated that the overall model for infant health severity predicting family burden when controlling for number of children, time since discharge, and number of stressful life events since the child's birth was significant, $F(14, 156) = 9.492$, $p < .001$, $R^2 = 46.0\%$. Parents of infants who were on ECMO during NICU hospitalization reported more family burden than parents of infants who were not on ECMO. Moreover, more medical devices during the NICU stay, higher number of specialists seen during the first-year post discharge, and higher number of medications the infant is currently prescribed at the time of the survey were associated with greater family burden. See Table 11 for additional information.

Results indicate that specific indices of infant health were associated with parental stress, couple functioning, and family burden. Specifically, use of ECMO during NICU stay, number of medical devices the infant used during NICU and at discharge, additional diagnoses following discharge, number of specialists seen post-discharge, and number of medications currently prescribed were significant predictors of parental stress, couple functioning, and family burden. Unexpectedly, a longer length of stay in the NICU was associated with less parental stress, and more rehospitalizations was associated with less parental stress and better couple functioning.

4.2.2 Hypothesis 2

The second hypothesis evaluated whether the relationship between infant health indicators, stress, couple functioning, and family burden were moderated by family resources when controlling for number of children, time since discharge, and number of stressful life events. This hypothesis was assessed using moderation analyses (Preacher & Hayes, 2008). A moderator impacts the relationship between two variables, such that the impact of a predictor variable on an outcome variable changes in direction or strength depending on the level of the moderator (Baron & Kenny, 1986). This analysis was conducted using PROCESS (Hayes, 2013) in SPSS. PROCESS is a macro program that uses ordinary least squares or logistic regression-based path to analyze mediation and moderation analyses (Hayes, 2013). Parental report of infant health indicators that were significant predictors in Hypothesis 1 for each specific outcome were included as the predictors and family resources was included as the moderator. A moderation analysis was conducted for each individual predictor. Parental stress, couple functioning, and family burden were run as separate outcomes. The covariates included time since NICU discharge, number of children in the household, and number of stressful life events since infant's birth.

For parental stress, three separate models were examined based on the significant predictors in Hypothesis 1 (length of stay in NICU, presence of additional diagnoses, and number of rehospitalizations). For this outcome, model one included length of stay as the predictor, family resources as the moderator, and time since discharge, number of children, and number of stressful life events as covariates. The overall model for length of stay and family resources predicting parental stress was significant, $F(6, 160) = 2.122$,

$p = .054$, $R^2 = 17.4\%$. Family resources significantly predicted parental stress (see Table 12). However, length of stay in the NICU and the interaction between family resources and length of stay were not significant. Model two included the presence of additional diagnoses after discharge as the predictor, family resources as the moderator, and the same covariates. The overall model for additional diagnoses and family resources predicting parental stress was significant, $F(6, 158) = 6.038$, $p < .001$, $R^2 = 24.3\%$. The main effect for family resources and additional diagnoses were significant, however, they did not significantly interact to predict parental stress (see Table 12). Finally, model three included number of rehospitalizations as the predictor, family resources as the moderator, and the same covariates. The overall model explained a significant proportion of the variance in parental stress, $F(6, 160) = 4.553$, $p < .001$, $R^2 = 17.5\%$. The main effect of family resources predicting parental stress was the only significant relationship in this model (see Table 12).

For couple functioning, two models were examined based on Hypothesis 1. Specifically, number of medical devices infant used at discharge and number of rehospitalizations were entered as separate predictors with family resources being the moderator when controlling for time since discharge, number of children, and number of stressful life events. The overall model for number of medical devices at discharge and family resources predicting couple functioning was significant, $F(6, 174) = 4.880$, $p < .001$, $R^2 = 21.2\%$. The main effects for family resources and number of medical devices at discharge were both significant, however, the interaction was not (see Table 13). The next model included number of rehospitalizations as the predictor, family resources as the moderator, and couple functioning as the outcome when controlling for the same

covariates. The overall model explained a significant proportion of the variance in couple functioning, $F(6, 174) = 4.639$, $p < .001$, $R^2 = 20.4\%$. Family resources and number of rehospitalizations were significant predictors for couple functioning, but the interaction was not significant.

For family burden, four models were run based on the significant predictors in Hypothesis 1. The predictors included whether infant was on ECMO during NICU stay, number of medical devices infant used during NICU stay, number of specialists seen since discharge or during first year following discharge, and number of medications the infant is currently prescribed at the time of the survey. Family resources was included as the moderator and time since discharge, number of children in household, and number of stressful life events since the child's birth were entered as covariates for each model. The overall model for ECMO and family resources predicting family burden was significant, $F(6, 156) = 3.388$, $p = .004$, $R^2 = 12.2\%$. The main effect of family resources on family burden was the only significant finding in the model. The presence of ECMO during NICU stay and the interaction between ECMO and family resources were not significant. See Table 14. Overall, number of medical devices used during NICU stay, family resources, the interaction, and covariates explained a significant proportion of variance in family burden, $F(6, 160) = 8.786$, $p < .001$, $R^2 = 21.5\%$. Family resources and number of medical devices infant used during NICU stay were significant predictors of family burden, but the interaction was not (see Table 14). The overall model for number of doctors and family resources predicting family burden was significant, $F(6, 161) = 18.315$, $p < .001$, $R^2 = 37.4\%$. The main effects of number of doctors and family resources on family burden were significant, but the interaction was not significant (see

Table 14). Finally, number of medications and family resources explained a significant proportion of variance in family burden when controlling for covariates, $F(6, 160) = 7.312$, $p < .001$, $R^2 = 26.6\%$. Specifically, family resources and number of medications were significant predictors of family burden. However, they did not significantly interact to predict family burden (see Table 14).

Results indicate that family resources did not serve as a significant moderator for the relationships between infant health indicators and parental stress, couple functioning, and family burden. However, it was a significant individual predictor for each of these outcomes.

4.2.3 Hypothesis 3

The third hypothesis examined differences between men and women among all dependent variables. An analysis of covariance (ANCOVA) was conducted to evaluate differences; however, women ($n = 182$; 91.5%) significantly outnumbered men ($n = 17$; 8.5%), making this statistical test underpowered. The findings can be interpreted as preliminary at best. Sexes were compared on each outcome measure. The covariates included time since NICU discharge, number of children in the household, and number of stressful life events since infant's birth.

ANCOVA indicated that men and women did not differ on parental stress when controlling for time since discharge, number of children, and number of stressful life events, $F(1, 174) = 3.308$, $p = .071$. Men and women did not differ on reported couple functioning when controlling for covariates, $F(1, 189) = .087$, $p = .769$. Finally, men and women did not differ on reported family burden when controlling for covariates, $F(1,$

177) = 1.357, p = .246. More men would have to be included in the sample to determine any true sex differences in these outcomes.

4.2 Exploratory Analyses

Additional analyses were conducted to examine whether parental reproductive history (i.e., used fertility treatment in past and/or to conceive NICU child) and certain socio-demographic variables (i.e., parental education, income, and age) were related to parental and family outcomes. Analyses of covariance (ANCOVA) were used to examine if parents who had conceived their NICU child through fertility treatments or ever used fertility treatments reported more negative parental and family outcomes compared to those who had not. ANCOVA were conducted to examine differences in parental stress, couple functioning, and family burden as a function of education level and income. In all ANCOVA analyses, time since discharge, number of stressful life events since the child's birth, and number of children were included as covariates. Based on the sample sizes, education was recoded into two categories: participants who did not finish college (n = 85; 42.7%) and those who had a college or advanced degree (n = 111; 55.8%). Annual income was recoded into three categories: participants who make $49,999 or less ($n$ = 67; 33.7%), those who make between $50,000 - $99,999 ($n$ = 84; 42.2%), and those who make $100,000 or more ($n$ = 47, 23.6%). A series of bivariate correlations were conducted to examine the relationships between parental age and each outcome.

Parents who conceived their NICU child through fertility treatments (compared to those who did not) did not report more parental stress, $F(1, 14) = .000$, p = .985, worse couple functioning, $F(1, 15) = .086$, p = .773, or more family burden, $F(1, 16) = .321$, p = .576, when controlling for stressful life events since the child's birth, number of children,

and time since discharge. Additionally, parents who had ever used fertility treatments in the past (compared to those who did not) did not report more parental stress, $F(1, 172) = 1.360$, $p = .245$, worse couple functioning, $F(1, 187) = .230$, $p = .632$, or more family burden, $F(1, 174) = 2.496$, $p = .116$ when controlling for the covariates. However, due to the small sample size of participants who had utilized fertility treatments in the past ($n = 22$; 11.1%) whether it was for NICU child or not, analyses were underpowered and therefore cannot be deemed interpretable. Similar to the ANCOVA used to assess sex differences, at least 60 participants would need to be included in each group in order for tests of differences to be powered.

ANCOVA revealed that parental stress, $F(1, 171) = .655$, $p = .420$, couple functioning, $F(1, 185) = 1.420$, $p = .235$, and family burden, $F(1, 173) = .391$, $p = .532$, did not differ as a function of parental education when controlling for time since discharge, number of stressful life events, and number of children. Moreover, parental stress, $F(1, 171) = 1.078$, $p = .343$, couple functioning, $F(1, 186) = .988$, $p = .374$, and family burden, $F(1, 174) = 1.112$, $p = .331$, did not differ as a function of income when controlling for covariates. Finally, parental age was not associated with parental stress ($r = .080$, $p = .288$), couple functioning ($r = -.111$, $p = .127$), or family burden ($r = -.069$, $p = 358$). Maternal age was also not associated with parental stress ($r = .131$, $p = .097$), couple functioning ($r = -.132$, $p = .082$), or family burden ($r = -.044$, $p = .577$). Partial correlations, which can control for the covariates, were also not significant.

5. DISCUSSION

5.1 Purpose

The transition to parenthood is challenging. A newborn child poses substantial demands on a family and this transition is among the most stressful life events that many individuals experience (Leigh and Milgrom, 2008). An ill infant can create a host of psychological, physical, and social problems for parents because an extra burden is added to an already difficult transition. In particular, the NICU can be a scary and intimidating place for parents. Even after NICU discharge, infants remain at increased risk for ongoing health problems and parents often have to deal with the associated responsibilities and stressors. The NICU experience and what happens after discharge varies dramatically among families. The severity of an infant's health and the burden of care associated with it are key elements for long-term parental and family psychosocial adjustment.

The current study was designed to build upon and extend the current literature by examining the experience of mothers and fathers of infants with various medical disorders who spent time in a NICU several months to several years following discharge. Parents reported infant health characteristics during NICU admission and at the time of survey administration; stress related to parenting and their child; elements associated with the couple's relationship; parental perception of the burden a child has on the family; and perception of family resources. The present study examined how parental report of infant health characteristics impacted parental stress, couple functioning, and family burden six months to three years post-NICU discharge. Family resources were assessed as a moderating variable, and sex differences were examined, although given the limited

number of males relative to females, these analyses were underpowered and results can only be considered preliminary.

5.2 Participant and Infant Characteristics

A majority of study participants were White married women who identified as Christian (includes all forms of Christianity that do not identity with Catholicism) (see Table 1). Moreover, the largest percentage of participants had graduated college and most participants were stay-at-home parents or employed full-time (see Table 1). A majority of the participants were not the sole caregivers for the child, which was expected given that participants had to have been in an intimate relationship with their partner from NICU admission. These sample characteristics may be a result of the recruitment procedures. The sample was recruited mostly through the Internet on social media websites. Research indicates that social media users are most likely to be mothers (rather than fathers) with at least some college education and with higher income households ($50,000 - $75,000 and greater) (Pew Research Center, 2015a; 2015b).

A number of participants and their partners had experienced a pregnancy loss in the past and some had undergone some fertility treatment in the past, with most of them having conceived the child in the NICU through the use of fertility treatments (see Table 2). The data on participants' reproductive histories reflect their various journeys to parenthood, emphasizing the important context in which the NICU experience exists as an adverse reproductive event. Research indicates that fertility treatments are stressful events that can take a psychological toll on parents. Fertility treatments often have low levels of success, are costly, and can negatively impact a woman's self-efficacy, body image, and marital relationship (Cousineau & Domar, 2006; Schmidt, Holstein,

Christensen, & Boivin, 2005). As a result, parents who have conceived their child through fertility treatments and have their child admitted to a NICU are adding additional stress to an already challenging experience. However, in the current sample, parents who used fertility treatment to conceive their NICU child did not report poorer outcomes. It is possible that parents who used fertility treatments have a different perspective than parents who had not undergone these stressors in the past. However, results were underpowered, so further research is needed to understand how reproductive history may play a role in adjustment for NICU families.

The infant health characteristics varied greatly among families. The gestational ages of infants ranged from extremely preterm (<28 weeks) to post-term (>40 weeks) and birth weights ranged from extremely low birth weight (<1000 grams) to normal weight (>2500 grams). Some infants were in the NICU for less than a week while others were there for almost six months (see Table 3). Moreover, infants were on a range of medical devices during the NICU stay (although very few were on ECMO) and most infants were not discharged or on any medical devices at the time of survey administration (see Table 4). Diagnoses ranged drastically, but many infants experienced apnea and/or reflux. The most common diagnosis category was pulmonary/respiratory issues, which included apnea, respiratory distress syndrome, and chronic lung disease (see Table 5). A number of infants had been diagnosed with an additional medical condition following discharge and almost half of those were developmental disabilities. Most infants were not rehospitalized following discharge, but 25.5% of them were rehospitalized. A number of infants were currently on medications at the time of survey administration and most had to see at least one additional specialist besides the pediatrician (see Table 6). The diverse

medical conditions highlight the assorted experiences of families who have an infant spend time in a NICU, which greatly differs from the typical experience of families with full term infants without medical conditions or any hospitalizations.

5.3 Preliminary Analyses

5.3.1 Descriptive Statistics on Primary Variables

Descriptive statistics of all quantitative self-report measures were examined. Parental stress, as measured by the PSI-SF, ranged from the lowest possible reported score (36) to significantly high levels of stress, although not reaching the maximum value of 180. In fact, 20.44% of participants reported scores of 90 or higher, indicating clinically relevant, severe parental stress. The distribution for the sample was positively skewed meaning the scores tended to fall below the average of a normally distributed sample. These data suggest a few possible interpretations. Previous literature indicates that parental stress is most often associated with delayed parent-infant attachment and uncertainty in the parenting role (Obeidat et al., 2009). Although parenting stress remains high during the first few years following discharge, it may be decreasing with time as parents adjust to their role and form a stronger relationship with their child. Moreover, the retrospective self-report design of the study may remind parents of the challenging time in their life and how they have adjusted to their "new normal." Parents may have witnessed an improvement in their infants' health status and/or have accepted the infant's medical condition, which might help them to feel grateful for their child and to have the opportunity to be a parent. Furthermore, participants may have been motivated to portray themselves and their parental role in a positive light due a social desirability bias or they might be engaging in self-report bias by underreporting their stress to minimize their

problems or because they are in denial about the severity of their stress. Finally, it is possible that the NICU experience served to ease parental stress due to the knowledge, skills, and support that parents had from the medical team during hospitalization.

Couple functioning, as measured by the RDAS, was negatively skewed compared to a normal distribution meaning participants reported better than average couple functioning. This finding could be due to a variety of factors. The literature examining the impact that a NICU child has on the parental relationship is sparse (Manning, 2012). Childhood chronic illness literature that examines parental relationships indicates that there may be positive and negative effects of this experience on the couple. Depending on the resources available to parents, coping strategies, and their perspectives, this experience can bring parents together or drive them apart (Manning, 2012). For parents with a child with cancer, increased marital satisfaction occurs when parents realize that they have the ability and resources to manage together all of the challenges the cancer presents. Decreased marital satisfaction occurs with high stress, little time dedicated for the intimate relationship, and deterioration in intimacy and connection (Silva, Jacob, & Nascimento, 2010). In families with an extremely low birth weight infant, both positive and negative effects on marriage were found to be higher than families of normal weight infants (Saigal et al., 2000). The negatively skewed distribution may be a result of parents reconnecting after leaving the NICU: perhaps after at least six months post-NICU discharge, they realize that they are able to manage the child's illness together. Furthermore, an inclusion criterion of the study was that parents must be living together and with the infant since discharge. This inclusion criterion may have contributed to the higher couple functioning scores, as parents who stay together during this difficult time

and for up to three years later may be ones with a stronger intimate relationship. Conversely, parents may also be engaging in self-report bias or social desirability by reporting higher than average scores.

Family burden, which was assessed by the IOF-R, ranged dramatically within the sample (0 - 59) and was similar to the total possible range (0 - 60). Overall, the data was positively skewed meaning the sample reported less family burden than a normally distributed sample. The measure was created to assess how a child's illness impacts the perceived burden on the family. There are some participants in the sample that had a child spend time in a NICU, but whose child no longer has any medical issues. As a result, these low scores may have skewed the distribution. Nevertheless, family burden was positively correlated with many infant medical issues and there were families with high self-reported burden (see Table 8). The distribution is not of much concern given that the range of scores for the sample was similar to the possible range, the analyses were powered, and no assumptions (i.e., linearity, independence, normally distributed errors, homoscedascity, and multicollinearity) were violated. In addition, preliminary analyses suggest that the strong correlations between infant health and family burden make it a good candidate for further multiple regression analyses.

Family resources (i.e., basic needs, money, time for self, time for family), which was assessed by the FRS-R, was negatively skewed indicating that the sample reported having more perceived family resources than would be expected on a normal distribution. This finding is not surprising given the socio-demographics of the sample. A majority of participants were White, married, college-educated, full-time or stay-at-home employment statuses, and middle class incomes. Given the relative homogeneity of the

sample and the way that most participants were recruited (via social media websites), the participants were expected to have adequate resources.

5.3.2 Bivariate Correlations

Bivariate correlations were conducted to examine initial relationships among primary variables (see Table 8). Parental stress was positively correlated with number of medical devices used (during NICU, at discharge, and at present time) and number of specialists seen during the first year post-discharge. The infant health characteristics represent the severity of the infant's conditions as well as the burden of care for parents. In this case, most of the variables associated with parental stress are representative of burden of care. In other words, parental stress may be more impacted by the extra responsibilities that are associated with managing a child's illness than the actual severity of the condition. Research indicates that although the stressors experienced by parents of children who are chronically ill are multiple and ongoing, common stressors include diagnosis, developmental transitions, and dealing with the ongoing health care needs of their child (Melnyk, Feinstein, Moldenhouer, & Small, 2001). In this specific case, parents must be able to understand how to use medical equipment in order to care for their infant at home. Additionally, driving a child to and from doctor appointments requires time, energy, money, transportation, and adequate health insurance. Doctor offices can be onerous and the more specialists that their infant is required to see, the greater the burden they are experiencing.

Couple functioning was inversely related to medical devices at discharge and parental stress. In other words, more medical devices at discharge and more parental stress were associated with poorer couple functioning. High levels of stress are going to

greatly impact the couple's relationship. Research indicates that couples have different adaptive processes (e.g., communication, commitment) to help them cope with the stressors placed on their relationship functioning (Doss et al., 2010). Similar to the patterns observed in parenting stress, couple functioning is impacted by a variable that seems to be indicative of the burden of care associated with taking a NICU child home. Infants with a high number of medical devices at discharge require parents to be educated on the devices and manage the child's illness during a time that is especially stressful, as they are suddenly without the assistance of a medical team. These analyses suggest that couple functioning may be most impacted during a highly stressful transitional event (leaving NICU and coming home). Interestingly, this is the only variable that represents the immediate transition home as the others all represent either NICU admission or current health status. It may be that the parental relationship experiences the greatest decline when parents are most vulnerable and transitioning from a supportive NICU environment to the home environment – one that requires both of them to be actively engaged and work together to manage their child's illness, possibly creating tensions and conflicts between them.

Interestingly, family burden was associated with all infant health indicators (i.e., gestational age; birth weight; length of stay in NICU; number of medical devices during NICU, at discharge, and at the current time; rehospitalizations; and number of specialists). Family burden was also associated with increased parental stress and poorer couple functioning. Based on the analyses, infant health indices seem to be most influential for family burden. These findings are not surprising given the nature of this variable (the perceived burden due to the child's illness), but it is imperative to note

because it demonstrates the psychosocial and physical toll that an ill infant can have on families. For these families, it may be especially complex if there are other children at home who also require time, energy, and care. An ill child and the associated demands and attention that they require can disrupt the family system. It is vital to understand the NICU family as a whole because the NICU experience may be an isolated event, but the contextual factors within the family must be considered and understood to fully understand this journey.

Possession of fewer family resources was associated with poorer couple functioning and more family burden, but was not associated with parental stress. It is fascinating that the resources available to the family seem to be more important for dyadic and family functioning rather than individual stress levels. Doss and colleagues (2010) reported that lower individual incomes (but not more financial stress) tended to predict more deterioration in relationship functioning after a child's birth. Therefore, it appears that additional resources and support afforded by a higher income serves to buffer the relationship from declines in relationship quality. Family resources have been shown to buffer against couple and family impact and fewer family resources have been linked to greater family burden (Stephens et al., 2008).

5.4 Main Analyses

5.4.1 Hypothesis 1

Hypothesis one was partially confirmed. Infant health was predictive of parental stress, couple functioning, and family burden; however, the specific indices and direction of associations were varied.

5.4.1.1 Parental Stress

For parental stress, a longer length of stay in the NICU and more infant rehospitalizations predicted less stress. In addition, parents of infants who were diagnosed with an additional medical condition (about half were developmental disabilities) following discharge reported more parental stress compared to parents of infants without an additional diagnosis following discharge.

It was surprising that more time in the NICU and more rehospitalizations were associated with less parental stress. Past research indicates that immediately following NICU admission, rehospitalizations and medical complications become a main source of stress for parents (Brummelte et al., 2011). Additionally, a consistent predictor of parental stress in the NICU has been extreme prematurity and a longer length of stay (Dudek-Shriber, 2004). However, research also suggests that the NICU sights and sounds (i.e., noises, machines, lights) cause little stress for parents because the environment is perceived to be helping to keep the baby alive, and that parents become increasingly familiar with the NICU environment over time (Dudek-Shriber, 2004). These seemingly contradictory findings have important implications and can be interpreted in a couple of ways. First, it could be that a longer length of stay in the NICU provides more educational opportunities for parents to learn about the infant's condition, connect with the medical team, and develop skills and knowledge necessary to care for their child once they are discharged. Parents with infants who are in the NICU for a longer time period may have time to build relationships with the medical team that could aid in lowering their stress levels and allow them to feel comfortable asking difficult questions about their child's illness and prognosis. Moreover, adjusting to this environment may provide

more time to cope with their child's medical illness while having medical professionals (e.g., nurses, neonatologists, occupational therapists, social workers, psychologists) readily available to them for a longer period of time. It would be beneficial to do a qualitative assessment with these participants to learn about their experiences in the NICU, their communication patterns with the medical team, and their perception of the support and knowledge they received during that time. Second, the education level of this sample (i.e., 55.3% of participants had at least a college or advanced degree) may have played an important role. Parents who are more educated can inquire more deeply about the child's condition, understand the information they receive, and more effectively communicate with the medical staff and their family members. Educated parents are more likely to take advantage of educational opportunities in the NICU to learn the skills and knowledge necessary to handle their child's condition, which may serve to buffer against increased stress. Finally, because the study's design is retrospective, parents with infants who spent more time in the NICU may be reminded of that difficult time and therefore current stress related to parenting may seem trivial in comparison leading to an underreporting of current stress levels.

More infant rehospitalizations during first year post-discharge was associated with less parental stress. Similar to the pattern observed in length of stay, more rehospitalizations increase contact hours between parents and the medical team. Parents receive additional opportunities to get their questions answered from trained medical staff and may learn additional information on managing their child's condition(s). Because the transition home can be the most challenging time for NICU parents, parents may be appreciative for opportunities to check in with medical staff and may help them to feel

less anxious and worried about their child. Parents may learn from the staff about warning signals for the child's health and how to better handle medical crises. It would be helpful to know if there are any potentially mediating variables such as parents' comfort level managing their child's illness, accessibility of the medical team, parent perception of disease management and skills caring for child's illness, and support from medical team. A more diverse and representative socio-demographic sample and understanding of the parents' medical experiences would provide a fuller understanding of the relationship between length of time in the NICU, rehospitalizations, and parental stress.

Consistent with previous literature, parents with infants with additional diagnoses following discharge reported more parental stress than parents with infants without medical issues. Saigal and colleagues (2000) reported that parents of 12 or 16 month old children with a variety of impairments reported more emotional stress than those with children without impairments. Extremely low birth weight infants with medical complications require a larger time commitment and cost for parents (Stephens et al., 2009). Based on the findings, any additional condition diagnosed after discharge (whether it is developmental disability or not) can enhance stress for parents.

It is interesting to note that other health indices (i.e., birth weight; use of ECMO; number of medical devices during NICU, at discharge, and at current time; developmental disability; number of specialists; and number of medications) were not associated with increased parental stress. The NICU health indices (i.e., birth weight, ECMO, number of medical devices) may have created stress for parents during their infant's NICU stay, but are no longer factors in their current stress levels. Additionally, although current health issues may be difficult for parents and create family strain (e.g.,

requirement of more time and resources, balancing multiple children), parents may have adjusted to the daily stressors over time and as a result do not report high levels of stress related to parental responsibilities. Also, these parents may be thankful that their child is alive despite the medical issues, and therefore may have a different perspective when dealing with the normal stressors associated with parenting.

5.4.1.2 Couple Functioning

Similar to the patterns observed in parental stress, a greater number of infant rehospitalizations during the first year following discharge was associated with better couple functioning. However, more medical devices at discharge was associated with worse couple functioning.

Again, more rehospitalizations allow parents to have extra face time with trained medical staff. As such, they may receive more information about the child's illness, how best to manage it, and how to handle crisis situations, thereby improving parental competence and confidence. In contrast, more medical devices at discharge was predictive of poorer couple functioning. Intriguingly, this health indicator is the only one that is representative of the immediate transition from NICU to home. The initial transition home may be the most difficult time for a couple as they work together (without the assistance of the medical team) to take care of their child. Being discharged on multiple medical devices makes things much more complicated and parents may disagree on how to manage the child's illness, deal with work and employment, take care of other children, handle finances, and manage other ongoing responsibilities. Past research is mixed regarding the impact of an ill child on parental relationships. Some parents report that having an ill child brings them closer together, while others report

more conflict and strain (Saigal et al., 2000). The current findings are in line with the previous literature. The parental relationship was both positively and negatively affected by the infant's health. Further research should continue to examine how specific variables/situations within this experience (i.e., relationship with NICU staff, knowledge of disease management, transition home) impact the couple's communication, coping styles, and ultimately, relationship functioning and satisfaction.

5.4.1.3 Family Burden

For family burden, infant use of ECMO, number of medical devices infant used during NICU stay, number of specialists infant saw first year post-discharge, and number of medications infant is prescribed at the time of survey were predictive of greater family burden. Family burden includes the fatigue that parents feel from their child's illness, the lack of time they spend with friends and other family members, and the perceived burden their carry.

Use of ECMO and number of medical devices at admission represent the severity of the infant's medical condition during the NICU. ECMO is a treatment used for patients with life-threatening heart and/or lung problems. Infants on ECMO are some of the most severe cases in a NICU. Additionally, infants who are on more medical devices (i.e., oxygen, ventilator, feeding tube, tracheostomy, phototherapy, Replogle Tube) are experiencing a variety of medical issues that require ongoing support from these machines, representing more severe medical conditions. During the NICU stay, having a child connected to many large machines can be overwhelming and terrifying for parents. The severity of the infant's condition during NICU admission seems to be an important construct for later perceived family burden.

Moreover, number of specialists the infant saw first year post-discharge and number of medications the infant is prescribed at the time of the survey are predictive of greater family burden. These variables represent the burden of care associated with having a NICU infant meaning they require more time, energy, money, and resources from caretakers (parents). Visits to medical specialists can be expensive, time-consuming, and taxing. Infants who must see more specialists are experiencing various medical, psychological, or social issues and parents have less time for themselves, siblings and other family members as a result. Furthermore, parents with infants prescribed multiple medications must be aware and educated on their medication schedule, make sure their child is maintaining medical adherence, and check in with specialists about their child's reaction to medications, development, and ongoing health concerns. In sum, the severity of the child's condition during NICU admission and the burden of care associated with the child's current needs seem to be most critical to the parental perception of family burden.

Of interest, other variables related to current infant disease severity such as additional diagnoses and developmental disabilities following discharge were not significant predictors of family burden. Based on the findings, the care that infants require at the present time seems to be more burdensome than their current disease severity. Additionally, disease severity during the NICU stay (i.e., use of ECMO and number of medical devices) contributed to family burden. The NICU experience may have been traumatic for parents as they watched their small infant on large, intimidating machines day in and day out. Parents may still be healing from the journey and may not be aware of the long-term impact that the experience had on their current perception of

their child and family. Moreover, this distress may have had longstanding effects on the family and parental relationships with the child, which, in turn, led to family adversity.

5.4.1.1 Summary of Hypothesis 1

Together, these findings add valuable information to the current literature. First, a longer length of stay in the NICU was associated with less parental stress, and more rehospitalizations was associated with less stress and better couple functioning. These findings suggest that additional time with medical staff may provide parents with more in depth knowledge and enhanced skills to manage their child's illness following discharge. The transition home is difficult for parents, especially when child requires additional care. Specifically, parents with infants who were diagnosed with an additional diagnosis following NICU discharge reported more parental stress than those without an additional diagnosis. Number of medical devices at discharge was associated with poorer couple functioning. Parental stress and the parental relationship suffer as a result of more medical issues and burdensome care. Finally, parents of infants who were on ECMO (compared to those who were not) and with more medical devices during NICU stay (compared to those with less), reported greater family burden. The severity of the child's condition during hospitalization and the NICU environment may be overwhelming for parents and place a greater strain on their resources (e.g., money, time, energy). Parents with infants who were required to see more specialists following discharge and who are prescribed a higher number of medications reported greater family burden. These findings are consistent with previous literature indicating that ongoing medical complications of the child can greatly impact the financial, social, and occupational aspects of family life (Stephens, Bann, Poole, & Vohr, 2008). In addition, the more

dependent the child is on the caregiver, the more emotional impact the caregiver experiences (Stephens et al., 2008). These specific health indicators require more attention and care from parents, which ultimately have a more negative impact on the family.

5.4.2 Hypothesis 2

Hypothesis 2 was not confirmed. It was hypothesized that family resources would modify (i.e., change or strengthen) the relationships between infant health and parental stress, couple functioning, and family burden. Family resources did not significantly interact with infant health indicators to predict parental stress, couple functioning, and family burden. The health indicators that were included in each model as predictors were chosen based on their significance in Hypothesis 1.

Nevertheless, the main effect of family resources on each outcome was significant, meaning it was related to parental and family adjustment. Specifically, report of greater family resources was associated with less parental stress, poorer couple functioning, and less family burden. These findings support previous literature that family resources play a critical role in NICU family adjustment (Stephens et al., 2009; Treyvaud et al., 2011; Treyvaud 2014). Although the findings do not indicate that family resources (i.e., basic needs, money, time for self, and time for family) serve as a moderator for infant health and negative parental and family outcomes, family resources do significantly attenuate parental stress, poorer couple functioning, and family burden no matter how severe the child's health condition may be. These resources provide parents with more confidence and stability because they allow them to connect more easily with trained medical staff, feel more secure financially providing for their child,

assist with the care of other children at home, and provide more opportunity to seek out social or psychosocial support. Based on the current findings and existing literature, family resources play a significant role in preventing negative psychosocial sequelae, including increased stress, poorer couple functioning, and greater family burden.

5.4.3 Hypothesis 3

Hypothesis 3 was not confirmed. Men and women did not differ in parental stress, couple functioning, or family burden, suggesting that parents may be equally affected by the NICU experience and subsequent child health problems. These findings are in line with Hynan (2005) who reported that men and women do not differ in their psychological responses of having a child in the NICU. Moreover, Doering and colleagues (2000) reported that mothers and fathers do not differ in perceptions of family resources. However, the current literature on NICU mothers and fathers is mixed, mostly because studies are underpowered for men. Notably, the current analysis also was underpowered given the small sample of men who completed the survey. Therefore, these findings are preliminary at best.

The first few years can be particularly onerous for the primary caretaker (often the mother) as they manage the child and their illness, speak with and drive them to specialists, cope with the fact that their child may experience chronic health issues for the rest of their life, and maintain ongoing responsibilities and relationships. Examining the experiences of both parents, identifying similarities and differences, and creating psychosocial interventions that support both mothers and fathers is essential for improving the family dynamic as well as biopsychosocial developmental outcomes for the child.

5.5 Exploratory Analyses

Exploratory analyses were conducted to examine how reproductive history of the couple and socio-demographic variables impact parental stress, couple functioning, and family burden. Past research indicates that socioeconomic status, education level, and maternal age are factors that may be relevant to NICU parental and family outcomes (Stephens et al., 2008, Treyvaud et al., 2011; Treyvaud, 2014). Additionally Schappin and colleagues (2013) hypothesized that previous fertility treatment would impact parental stress, although it had not been assessed in previous literature.

Results indicated that parents who utilized fertility treatments in the past and/or to conceive their NICU child did not report more negative outcomes. It is possible that parents who underwent fertility treatments may have had different expectations about pregnancy and birth outcomes compared to parents who did not use fertility treatment. For example, expectations about the perfect pregnancy, birth, or child may have already been adapted and reappraised as they dealt with the psychosocial challenges of fertility treatment. However, due to the small sample of participants who had used fertility treatment, results were unpowered and more research is needed to understand whether previous reproductive stressful life events can serve as a risk or resilience factor to NICU family adjustment.

Parental education, income, and age did not significantly contribute to parental and family outcomes. It is possible that objective indicators of socioeconomic status or age may not be as critical as the perception of family resources available. Intriguingly, self-reported perception of family resources did significantly impact parental and family outcomes. Also, it could be that other factors are explaining the variance in these

outcomes. For example, the medical experience, relationships with the medical team, severity of the child's condition, and satisfaction and perception of social support may contribute to the relationships between these socio-demographic variables and NICU family adjustment. Further research should consider exploring additional socio-demographic variables (i.e., ethnicity/culture, religion, history of mental illness) as well as how the medical experience, satisfaction with medical team, and social support impact NICU parental outcomes and ultimately the child's biopsychosocial development.

5.6 Clinical Implications

Relatively few studies have examined parental outcomes for families with an infant who spent time in a NICU past the early postpartum period. This study is among the first to explicitly assess the impact that infant health (during NICU admission and up to three years after the child's birth) has on couple, family and parental stress. Prior research has focused on maternal responses to NICU admission, usually among mothers of preterm versus full term infants without other medical diagnoses (Brummelte et al., 2011; Gray et al., 2012; Howe et al., 2014). On the other hand, the current study included families coping with a variety of medical diagnoses. Additionally, the majority of research on parental mental health and family outcomes of families with preterm infants focuses on maternal self-report, with fathers rarely included (Treyvaud, 2014). The current study included both mother and male partner (including fathers) responses in order to understand differences and similarities in perceptions of stress, as well as couple and family impact. While limited data from male respondents was obtained for this investigation, data collection is ongoing in an attempt to collect additional data from this subgroup in order to inform the extant literature on sex differences for this population.

In addition to advancing knowledge in this field, the results have meaningful clinical implications. These findings provide worthwhile information on risk and resilience factors for negative psychosocial sequelae among parents, which may assist in the development and provision of interventions that help parents' transition from the NICU environment to a new normal. Parents must learn to manage their child's illness without medical team assistance, cope with their own frustrations and grief, maintain family and ongoing responsibilities, adjust to a life they may have never imagined, and for some transition to parenthood. Consequently, the transition home can be one of the most challenging times for parents. Psychosocial interventions that continue throughout this adjustment period may be fundamental in attenuating psychological sequelae and family burden for NICU parents as well as developmental outcomes for the child.

Infant's use of ECMO during NICU admission, number of medical devices used during NICU stay, additional conditions diagnosed following NICU discharge, number of medical devices used at discharge, number of specialists seen in the first year post-discharge, and number of medications prescribed at the time of the survey, were directly associated with parental stress, poorer couple functioning, and family burden. Together, these findings fit with current conceptualizations that parents of infants with increasing health severity who require more attention and care are more likely to experience stress, and poorer couple and family functioning (Balakrishnan et al., 2011; Schappin et al., 2013; Treyvaud, 2014). Parents with infants with any of these characteristics (i.e., ECMO, medical devices during NICU stay and at discharge, medical conditions following discharge, number of specialists, and number of medications) are at higher risk for poorer adjustment and may be more likely to develop clinically significantly mental

health symptoms. Parents of infants with more severe health problems should be targeted with early interventions that aim to improve parental understanding and management of the child's illness, medical provider and patient communication, and address adaptive ways to cope and seek medical and psychosocial support. More research is warranted to better understand the underlying mechanisms that may be explaining these relationships. It is possible the psychological distress and family strain associated with NICU admission and subsequent child health problems (e.g., neurodevelopmental impairments) damage parent-child interactions and attachment, which may, in turn, contribute to the bidirectional relationship between parental psychosocial functioning and child development. High levels of parental stress and depression have been associated with more behavior problems, lower developmental social skills for children, and reduced interactive play between parent and child (Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983). Future research should assess parent-child interactions, communication, and play to better understand how that may influence psychosocial adjustment for parents of more severely ill children who have experienced a NICU admission. Understanding the interwoven nature of these interactions and outcomes allows for a more complete perspective, which is necessary for developing effective treatments and support for NICU parents and children.

Conversely, a longer length of time in the NICU and more rehospitalizations were related to less parental stress and better couple functioning, suggesting that spending a longer time in the NICU and having more rehospitalizations attenuate resulting stress. These findings may speak to the fact that more face time and communication with medical staff is beneficial for parental and family adjustment. Although these results

contrast with previous literature, they provide practical insights. It is possible that the experience during NICU admission and relationships formed with the medical team are mediating the relationships between infant health and parental and family adjustment. Further research examining the qualitative experiences of NICU families during the hospitalization and rehospitalizations would be beneficial for understanding these relationships. Consequently, developing and implementing psychoeducational programs that begin during NICU stay and are continued at follow-up may be critical for attenuating negative psychosocial outcomes. Ideally, these interventions should be run by a multidisciplinary team (e.g., nurses, neonatologists, social workers, occupational therapists, psychologists) who can answer questions about the child's medical condition, teach parents skills for managing their child's illness at home, support them through the difficult transition home, and help parents to feel confident about their ability to care for and support their child.

Infant birth weight, developmental disability, and number of current medical devices the infant used did not significantly predict stress, couple functioning, or family burden. Some of these findings are in contrast with the literature. For example, birth weight was not a significant predictor, although researchers report that higher parenting stress has been associated with lower birth weight and families with infants born at lower birth weight reported more negative family impact (Schappin et al., 2013; Treyvaud, 2014). These research studies tended to examine parents of preterm infants compared to parents of full term infants. It is probable that because the current sample is all NICU parents, birth weight become less important when understanding differences between families of NICU infants with varying medical severity levels. The reason this factor may

not contribute as much variance to the outcomes in the current sample is because most infants admitted to the NICU are born preterm and with lower birth weights (March of Dimes Perinatal Data Center, 2011). Past researchers frequently compare low birth weight infants with normal weight infants and report significant differences in parental outcomes (Gray et al., 2012; Howe et al., 2014; Schappin et al., 2013). However, it may be that medical issues associated with low birth weight explain more of the variance in parental and family outcomes. The present study suggests that among a NICU sample, the medical issues that arise are more important determinants of parental and family adjustment than the objective birth weight of the infant.

Results also highlight the important role that family resources play in attenuating stress, negative couple functioning, and family burden. Although resources did not change or strengthen relationships between infant health and parental and family adjustment, they are vital to consider when identifying families who may need additional psychosocial support during NICU admission and at follow-up. Families who have fewer resources (i.e., basic needs, money, time) are at higher risk for severe stress, poorer couple functioning, and greater family burden for up to three years post-discharge. Ideally, the medical team, social workers, and psychologist(s) should work together to approach these families and provide additional support and assistance in getting what they need to help their child. Typically, social workers do an excellent job helping families connect to insurance companies, determining transportation options, and assisting with time management. However, developing supplementary strategies for managing logistics and stressors associated with money, time, and needs would be

beneficial for all families, especially those with fewer resources (no matter how ill their child may be during NICU and post-discharge).

Finally, no sex differences in parental and family outcomes were observed. Based on these findings and those of Hynan (2005), men and women should be treated similarly in the NICU. During NICU hospitalization, women and men are often treated differently, even though they respond well to comparable methods of comfort (Abo, Friesen, Bonacquisti, Eichenbaum, Grady, Khaksari, Geller, & Patterson, 2014). Although women and men are both experiencing psychological distress, their sources of stress may be different. Mothers have reported that better communication and support from health care professionals about their infant is critical, whereas altruistic behavior and self–related needs ranked second (Bialoskurski, Cox, & Wiggins, 2001). In contrast, for fathers, being able to be at the hospital and be involved in their infant's care has a moderating effect on fathers' sense of control (Lindberg, Axelsson, & Öhrling, 2007). Abo and colleagues (2014) suggest that healthcare professionals should attempt to break these socialized barriers by facilitating bonding with father and infant physically or by taking interest in the fathers' lives outside of the NICU. Researchers, clinicians, and medical professionals should be aware that men and women are both experiencing stress and burden from their child's NICU admission and their subsequent health problems. Further investigation on the support that mothers and fathers need, and the differences in perceived stressors, would provide further insight in how best to develop integrated programs and support in the NICU and at follow-up, to address the specific needs of both mothers and fathers.

5.7 Limitations and Future Directions

The current study had several limitations that constrain the generalizability of the results. The online nature of the study design resulted in a high number of participants who did not meet inclusion criteria or did not complete the survey in its entirety (50.74%). Future researchers might consider collecting data in-person. By utilizing an in-person recruitment strategy, more people are likely to meet inclusion criteria and complete the survey. They would be specifically targeted based on these criteria and more accountable to finish the survey with a research assistant present.

A particularly striking finding in the current research was that women participated in the online survey at a much higher rate than men (almost eleven to one). This finding may help explain why NICU fathers have received so little research attention and why the few studies that do include fathers are underpowered (Treyvaud, 2014). For the current study's recruitment, father support groups were contacted to help spread the word to NICU dads. The number of NICU father groups was sparse with smaller memberships compared to NICU mother or parent support groups. The current findings could result from the fact that fathers are less likely to be on social media, they may be less willing to share their experiences, or their partners may not have encouraged them to participate (or even told them about the study). Future research needs to consider more creative ways to reach NICU fathers and encourage their participation. For example, recruiting in-person at pediatrician offices, multiple NICU follow-up clinics, and other specialist offices may be a more effective way to reach fathers following a NICU admission. Ideally, if healthcare professionals are the ones reaching out to fathers, this may increase credibility of the study and their willingness to open up about their experience. Future analyses will

assess whether this addition to recruitment increases male participation. If future research can recruit enough men to be powered for analyses, they also might want to consider matching the data for individual members of a couple to understand the dyadic experience as well as the similarities and differences in individual perspectives.

Other limitations of the current study include the self-report, cross-sectional, retrospective research design. Participants completed the survey online and anonymously, which affords advantages and disadvantages. This design increased accessibility of the survey as potential participants could find it online and complete it at any time that was convenient for them. Additionally, participants may have been more willing and open to share their NICU and subsequent experiences and provide more honest response than what may be obtained in an interview or in-person format. However, the self-report nature increases the chances of self-report bias and social desirability; participants may underreport negative experiences or attempt to be seen in a more positive light. Moreover, parents were asked to retrospectively report on their infant's health during a NICU admission, which may have been up to three years prior. As such, their memory and recall of the experience and the severity of the child's health may differ from what actually transpired. Future research may consider collecting information utilizing a longitudinal design. Specially, it would beneficial to asses the infant's health while in the NICU, parental stress and parental experiences in the NICU, and conduct a follow-up to measure the child's current health status as well as parental and family adjustment. Incorporating a follow-up assessment (or multiple time points) may diminish time-related effects that can skew parental perception of the experience. Additionally, it would be advantageous to collect data using a multi-method approach. Future studies may want to

supplement self-report data by collecting data using additional methodologies. For example, collecting data from medical professionals on the health severity of the child or adding a qualitative piece to understand medical/personal experiences would provide more information on the child's objective health and the hospital experience. Moreover, including clinical assessments of psychological functioning or directly observing behavioral interactions between parents, parents and infants, and the family, would provide a more comprehensive picture of parental psychosocial functioning. Finally, integrating biomarker measurements (e.g., biochemical assessments of stress such as cortisol and oxytocin or using Event-Related Brain Potentials (ERP) to assess brain activity in parents and children while they interact) would be noteworthy for identifying how parental and child neurobiological processes are impacted by these experiences, how parental and child biomarkers are related, and how neurobiological functioning aligns with psychological, emotional, and behavioral outcomes. Multiple methods of data collection would provide a more comprehensive understanding of the experiences of NICU families and how a NICU child and their health issues impact psychosocial adjustment, stress, relationship functioning, and attachment.

The infant health measure created for this study was based on variables in previous literature, a current review of knowledge, and consultations with NICU developmental psychologists and a neonatologist at CHOP. Necessary steps were taken so that the objective indicators of infant health minimized the subjective bias of parental report. Additionally, parents were able to answer the questions about their infant's health. However, parental report of infant health is subject to bias. Parents may not understand their child's health conditions fully, may be unaware of current complications (i.e., if you

are not primary caretaker), or may be inaccurate as the medical information can be confusing to parents. Future research is needed to validate this measure and assess its psychometric properties to determine whether the parental report of infant health is accurate and reliable. Furthermore, crosschecking parental report with medical staff knowledge would be extremely valuable for getting an accurate picture of the child's medical condition and severity.

Finally, the socio-demographics of the current sample are not representative of NICU parents nationwide. The study recruitment (via social media) captured a more educated sample of White women from higher socioeconomic brackets. Adding in-person recruitment, especially for women who may not have access to the Internet, would be helpful in sampling a more representative group of NICU parents. This finding limits the ability to draw conclusions about parental psychosocial adjustment for those with lower incomes, less education, fewer family resources, and who are more ethnicity/racially diverse. Future research should attempt to capture a more diverse sample characteristic of NICU families across the country through multiple methods and sites of data collection.

5.8 Summary and Conclusion

NICU family experiences are unique and diverse. Understanding the factors that impact adjustment and psychosocial outcomes is critical for improving and implementing psychosocial support and treatment for families. The current study highlighted the important role that infant health severity and its associated burden has on parental and family outcomes. Specifically, parents of infants who were receiving ECMO during NICU stay, diagnosed with an additional medical condition after discharge, were on high number of medical devices during NICU and at discharge, have many specialists, and

prescribed a high number of medications reported more parental stress, worse couple functioning, and greater family burden. In contrast, parents with infants who were in the NICU for longer periods of time and who had more rehospitalizations reported less parental stress and better couple functioning. Results indicated that infant health severity significantly predicted parent and family adjustment, however, more time spent with medical and support staff at the hospital may have attenuated the resulting impact. Additionally, family resources significantly predicted more negative outcomes, no matter how severe the child's condition. Finally, it was not possible to assess sex differences because analyses were underpowered. Overall, results suggest that further research to examine the medical experience and the positive impact that medical providers may be having on parental adjustment is warranted. Psychosocial interventions need to be developed and integrated into the NICU that focus on managing the child's illness, improving medical provider and parent communication and contact, improving coping strategies and family attachment, and addressing ways parents can receive adequate resources and support. Researchers should aim to recruit NICU fathers, in addition to mothers, to best understand their experiences; include multiple assessments to observe changes over time; and integrate assorted methodological approaches to provide the population of NICU parents with the attention, support, and resources that they truly need and deserve.

TABLE 1

Table 1. Participant Socio-Demographics Variables

	Total (*N* = 199)	**Females** (*n* = 182)	**Males** (*n* = 17)
Ethnic-racial background	***n (%)***	***n (%)***	***n (%)***
White	163 (81.9%)	148 (81.3%)	15 (88.2%)
African-American/Black	13 (6.5%)	13 (7.1%)	0
Latina/Latino/Hispanic	8 (4.0%)	8 (4.4%)	0
Bi/multiracial/ethnic[1]	7 (3.5%)	7 (3.8%)	0
Asian/Pacific Islander	4 (2.0%)	4 (2.2%)	0
Other	3 (1.5%)	1 (0.5%)	2 (11.8%)
Not reported	1 (0.5%)	1 (0.5%)	0
Relationship Status			
Married	169 (84.9%)	154 (77.3%)	28 (14.0%)
Unmarried, but living with partner	30 (15.1%)	15 (7.5%)	2 (1.0%)
Religion			
Christian[2]	104 (52.3%)	95 (52.2%)	9 (52.9%)
Catholic	33 (16.6%)	31 (17.0%)	2 (11.8%)
Not affiliated, but religious/spiritual	17 (8.5%)	15 (8.2%)	2 (11.8%)
No religious/spiritual identity	12 (6.0%)	9 (4.9%)	3 (17.6%)
Agnostic	11 (5.5%)	11 (6.0%)	0
Jewish	7 (3.5%)	7 (3.8%)	0
Atheist	6 (3.0%)	5 (2.7%)	1 (5.9%)
Other	8 (4.0%)	3 (1.6%)	0
Not reported	1 (0.5%)	1 (0.5%)	0
Education			
Some high school	2 (1.0%)	2 (1.1%)	0
High school graduate	13 (6.5%)	13 (7.1%)	0
Some college	49 (24.6%)	41 (22.5%)	8 (47.1%)
2-year college or Associate's degree	23 (11.6%)	22 (12.1%)	1 (5.9%)
4-year college or Bachelor's degree	67 (33.7%)	60 (33.0%)	7 (41.2%)
Master's degree	35 (17.6%)	34 (18.7%)	1 (5.9%)
MS/PhD/JD	8 (4.0%)	8 (4.4%)	0
Other	1 (0.5%)	1 (0.5%)	0
Not reported	1 (0.5%)	1 (0.5%)	0
Employment			
Employed full time	74 (37.2%)	62 (34.1%)	12 (70.6%)
Employed, but not working (e.g., maternity leave, FMLA)	3 (1.5%)	1 (0.5%)	2 (11.8%)
Employed part time	31 (15.6%)	31 (17.0%)	0
Home maker	74 (37.2%)	72 (39.6%)	2 (11.8%)
Full time student	5 (2.5%)	5 (2.7%)	0
Unemployed – Disability	3 (1.5%)	3 (1.6%)	0
Unemployed – Looking for work	4 (2.0%)	4 (2.2%)	0
Other	5 (2.5%)	4 (2.2%)	1 (5.9%)

[1] Bi/Multiracial/ethnic includes participants who identified as more than one racial/ethnic group

[2] Christian includes all forms of Christianity that do not identify with Catholicism

Income						
Less than $25,000	21 (10.6%)		19 (10.4%)		2 (11.8%)	
$25,000 - $49,999	46 (23.1%)		44 (24.2%)		2 (11.8%)	
$50,000 - $74,999	45 (22.6%)		39 (21.4%)		6 (35.3%)	
$75,000 - $99,999	39 (19.6%)		36 (19.8%)		3 (17.6%)	
$100,000 - $124,999	17 (8.5%)		16 (8.8%)		1 (5.9%)	
$125,000 - $150,000	14 (7.0%)		13 (7.1%)		1 (5.9%)	
More than $150,000	16 (8.0%)		14 (7.7%)		2 (11.8%)	
Not reported	1 (0.5%)		1 (0.5%)		0	
Sole Caregiver						
Yes	54 (27.1%)		52 (28.6%)		2 (11.8%)	
No	145 (72.9%)		130 (71.4%)		15 (88.2%)	
	M* ± *SD	***Range***	***M* ± *SD***	***Range***	***M* ± *SD***	***Range***
Parent Age	31.75 ± 5.34	18 – 50	32.94 ± 8.46	19 – 50	31.65 ± 4.99	18 – 45
Years Together	8.25 ± 4.23	1 – 23	8.56 ± 4.07	4 – 18	8.23 ± 4.26	1 – 23

TABLE 2

Table 2. Participant Reproductive and NICU History (*N* = 199)

Number of Children	***n***	**%**
1	95	47.7%
2	59	29.6%
3	31	15.6%
4	7	3.5%
5	6	3.0%
6	1	0.5%
History of Pregnancy Loss History		
Yes	70	35.4%
No	128	64.6%
Not reported	1	0.5%
If yes, how many pregnancy losses experienced?		
1	40	57.1%
2	14	20.0%
3	8	11.4%
4	2	2.9%
5	2	2.9%
7	1	1.4%
8	1	1.4%
11	1	1.4%
History of Fertility Treatments		
Yes	22	11.1%
No	176	88.9%
Not reported	1	0.5%
If yes, NICU child conceived via Fertility Treatment?		
Yes	15	68.2%
No	7	31.8%
Aware child would enter NICU?		
Yes	120	60.3%
No	78	39.2%
Not reported	1	0.5%
Currently Pregnant		
Yes	12	6.0%
No	187	94.0%

Note. Men reported on female partner's reproductive history.

TABLE 3

Table 3. Infant Health Characteristics during NICU Admission (*N* = 199)

	M* ± *SD	***Range***
Gestational age at birth (weeks)	31.54 ± 4.64	23 – 42
Birth weight (grams)	1791.54 ± 1000.82	453.59 – 5686.55
Length of time in NICU (weeks)	7.62 ± 6.30	0.29 – 30
Time Since NICU Discharge (weeks)	66.68 ± 44.65	6 – 177

TABLE 4

Table 4. Medical Devices and Extracorporeal Membrane Oxygenation (ECMO) (*N* = 199)

Medical Devices during NICU Stay	***n***	**%**
No medical devices	11	5.6%
Oxygen, Ventilator, & Feeding Tube	67	33.6%
Oxygen & Feeding Tube	49	24.6%
Feeding Tube	23	11.5%
Oxygen	15	7.5%
Oxygen, Ventilator, Feeding Tube, & Tracheostomy	12	6.0%
Oxygen & Ventilator	7	3.5%
Ventilator & Feeding Tube	5	2.5%
Oxygen, Feeding Tube, & Phototherapy	2	1.0%
Oxygen, Feeding Tube, Tracheostomy	2	1.0%
Replogle Tube	1	0.5%
Ventilator, Feeding Tube & Phototherapy	1	0.5%
Oxygen, Feeding Tube, & Replogle Tube	1	0.5%
Oxygen, Ventilator, Feeding Tube, Tracheostomy, & Phototherapy	1	0.5%
Not reported	1	0.5%
Medical Devices at Discharge		
No medical devices	133	66.8%
Cardiorespiratory monitor	20	10.0%
Oxygen	9	4.5%
Oxygen & Cardiorespiratory Monitor	7	3.5%
Feeding Tube	6	3.0%
Oxygen & Feeding Tube	5	2.5%
Oxygen, Cardiorespiratory Monitor, Feeding Tube	5	2.5%
Ventricular Shunt	3	1.5%
Not Specified	2	1.0%
Oxygen, Ventilator, Cardiorespiratory monitor, Feeding Tube, & Central Line	2	1.0%
Feeding Tube & Central Line	1	0.5%
Cardiorespiratory monitor & Feeding Tube	1	0.5%
Ventilator	1	0.5%
Oxygen, Cardiorespiratory monitor, & Not Specified	1	0.5%
Oxygen & Ventilator	1	0.5%
Oxygen, Ventilator, Cardiorespiratory monitor, Feeding Tube, Tracheostomy, Ventricular Shunt, Central Line	1	0.5%
Oxygen, Ventilator, Cardiorespiratory monitor, Feeding Tube, Tracheostomy, Ventricular Shunt, Central Line, & Not Specified	1	0.5%
Medical Devices Currently On		
No medical devices	176	88.4%
Feeding Tube	9	4.5%
Oxygen	4	2.0%
Oxygen, Cardiorespiratory Monitor, & Feeding Tube	3	1.5%
Nebulizer	2	1.0%
Oxygen & Feeding Tube	2	1.0%
Ventral Shunt	2	1.0%
Oxygen & Feeding Tube	2	1.0%
Cardiorespiratory Monitor	1	0.5%

Infant on ECMO during NICU Stay		
Yes	8	4.0%
No	185	93.0%
Not reported	6	3.0%

TABLE 5

Table 5. Infant Diagnoses (*N* = 199)

Diagnoses during NICU Admission	***n***	**%**
No diagnoses	38	19.1%
Pulmonary/Respiratory		
Apnea	62	31.2%
Respiratory distress syndrome	55	27.9%
Chronic lung disease	39	19.6%
Pulmonary hypertension	7	3.5%
Gastrointestinal		
Reflux	65	32.7%
Necrotizing enterocolitis (NEC)	6	3.0%
Cholestasis	2	1.0%
Cardiac		
Patent ductus arteriosus (PDA)	30	15.1%
Heart Murmur	25	12.6%
Heart defects	12	6.0%
Bradycardia	7	3.0%
Neurological		
Brain bleeds	20	10.1%
Intraventricular hemorrhage (IVH)	8	4.0%
Seizures	6	3.0%
Periventricular leukomalacia (PVL)	4	2.0%
Stroke	1	0.5%
Infectious Disease		
Group B streptococcus (GBS)	7	3.5%
Late onset sepsis	4	2.0%
Congenital Genetic		
Abdominal Wall Defects	2	1.0%
Down Syndrome	1	0.5%
Condition requiring surgery (most common)		
Hernia Repair	8	4.0%
Gastrostomy Tube (G-Tube)	4	2.0%
Ventricular Shunt Insertion	3	1.5%
Other (most common diagnoses)		
Retinopathy of Prematurity (ROP)	10	5.0%
Intrauterine growth restriction (IUGR)	6	3.0%
Anemia	5	2.5%
Meconium	3	1.5%

Note. For diagnoses during NICU admission, participants were able to select multiple diagnoses. When tabulating the data, we treated each diagnosis as its own entity. Often times, infants had multiple diagnoses.

TABLE 6

Table 6. Infant Characteristics after Discharge (*N* = 199)

Additional diagnoses after Discharge	***n***	**%**
Yes	54	27.4%
No	143	72.9%
Not reported	2	1.0%
Developmental Disability		
Yes	47	23.6%
No	151	75.9%
Not reported	1	0.5%
Number of Rehospitalizations		
0	146	73.4%
1	31	15.6%
2	15	7.5%
3	4	2.0%
4	1	0.5%
8	1	0.5%
9	1	0.5%
Currently on Meds?		
Yes	61	30.7%
No	138	69.3%
Number of Specialists (seen first year post-discharge, except for pediatrician)		
0	38	19.1%
1	39	19.6%
2	31	15.6%
3	26	13.1%
4	17	8.5%
5	17	8.5%
6	6	3.0%
7	10	5.0%
8	10	5.0%
9	2	1.0%
10	1	0.5%
11	2	1.0%

TABLE 7

Table 7. Total and Subscale Scores for Primary Variables

	M* ± *SD	***Range***
Parental Stress[3] (*N* = 181)		**36 – 180**
Total Score	73.72 ± 22.14	36 – 156
Parental Distress Subscale	30.96 ± 10.61	12 – 58
Parent-Child Dysfunction Interaction Subscale	19.61 ± 7.06	12 – 48
Difficult Child Subscale	23. 14 ± 8.11	12 – 50
Couple Functioning[4] (*N* = 196)		**0 – 69**
Total Score	46.37 ± 8.77	17 – 65
Consensus Subscale	22.73 ± 4.36	0 – 30
Satisfaction Subscale	12.85 ± 2.87	1 – 16
Cohesions Subscale	10.80 ± 3.33	1 – 19
Family Burden[5] (*N* = 184)		**0 – 60**
Total Score	16.80 ± 17.36	0 – 59
Family Resources[6] (*N* = 184)		**0 – 150**
Total Score	80.18 ± 16.17	16 – 105
Basic Needs subscale	32.95 ± 5.10	0 – 35
Money subscale	16.23 ± 6.21	0 – 25
Time for Self subscale	18.17 ± 6.25	0 – 30
Time for Family subscale	8.14 ± 1.67	3 – 10

Note. Higher parental stress scores indicate more stress. Lower couple functioning scores indicate more marital/relationship distress. Higher family burden scores indicate more family burden. Higher scores on family resources indicate more family resources.

[3] Parental Stress was measured with Parenting Stress Index, Short Form.
[4] Couple Functioning was measured with Revised Dyadic Adjustment Scale.
[5] Family Burden was measured with Impact on Family Scale Revised.
[6] Family Resources was measured with Family Resources Scale Revised.

TABLE 8

Table 1. Bivariate Correlations of Primary Study Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12
(1) Weeks Gestation	—											
(2) Birth weight	.83***	—										
(3) Length of time in NICU	-.77**	-.58***	—									
(4) Number of Med Devices (NICU)	-.41**	-.28***	.44***	—								
(5) Number of Med Devices (Discharge)	-.24**	-.20**	.39***	.27***	—							
(6) Number of Med Devices (Currently)	-.22**	-.22**	.45***	.12	.43***	—						
(7) Number of Rehospitalizations	-.15*	-.13	.23**	.07	.15*	.26***	—					
(8) Number of Specialists	-.46**	-.39***	.61***	.33***	.39***	.43***	.27***	—				
(9) Parental Stress	-.08	-.09	.09	.16*	.29***	.26**	-.02	.25**	—			
(10) Couple Functioning	.11	.11	-.06	-.03	-.22**	-.09	.07	-.10	-.49***	—		
(11) Family Resources	.02	.04	-.03	-.04	-.07	-.03	-.06	-.11	-.40***	.41***	—	
(12) Family Burden	-.35***	-.22**	.43***	.28***	.35***	.43***	.36***	.53***	.40***	-.18*	-.24**	—

Note. *$p < .05$, **$p < .01$, ***$p < .001$.

TABLE 9

Table 1. Infant Health Indicators Predicting Parental Stress

Model 1	**B**	**Std. Error**	**β**	**t**	***p***
Time since discharge	.017	.040	.034	.426	.671
Number of stressful life events	.541	1.107	.039	.489	.626
Number of children	2.799	1.627	.133	1.721	.087
Model 2					
Time since discharge	.030	.039	.061	.775	.439
Number of stressful life events	-.372	1.069	-.027	-.348	.729
Number of children	.704	1.541	.033	.457	.649
Birth weight	-.002	.002	-.102	-1.184	.238
Length of stay in NICU	-.886	.378	-.250	-2.345	.020
ECMO during NICU stay	12.817	8.200	.110	1.563	.120
Number of medical devices during NICU	2.538	1.656	.122	1.533	.127
Number of medical devices at discharge	2.527	1.529	.136	1.654	.100
Additional diagnoses after discharge	9.631	3.769	.202	2.556	.012
Developmental disability	5.007	4.103	.098	1.220	.224
Number of current medical devices	7.772	4.491	.170	1.731	.086
Number of rehospitalizations	-3.359	1.471	-.180	-2.284	.024
Number of specialists (besides pediatrician)	.920	.843	.110	1.092	.277
Number of medications on currently	2.158	1.354	.151	1.594	.113

Note. R^2 = .022 (p = .296) for Model 1; ΔR^2 = .244 (p < .001) for Model 2. The gray shading is used to indicate significant findings.

TABLE 10

Table 2. Infant Health Indicators Predicting Dyadic Functioning

Model 1	**B**	**Std. Error**	**β**	**t**	***p***
Time since discharge	-.030	.015	-.147	-1.941	.054
Number of stressful life events	-.786	.438	.136	-1.797	.074
Number of children	.039	.618	.005	.063	.950
Model 2					
Time since discharge	-.036	.016	-.177	-2.215	.028
Number of stressful life events	-.988	.454	-.171	-2.177	.031
Number of children	.471	.613	.056	.768	.443
Birth weight	.001	.001	.142	1.633	.104
Length of stay in NICU	.167	.157	.119	1.067	.288
ECMO during NICU stay	-5.415	3.196	-.124	-1.694	.092
Number of medical devices during NICU	.566	.712	.064	.795	.427
Number of medical devices at discharge	-1.845	.657	-.237	-2.807	.006
Additional diagnoses after discharge	-.615	1.623	-.031	-.379	.705
Developmental disability	.405	1.751	.019	.231	.818
Number of current medical devices	-1.230	1.762	-.070	-.698	.486
Number of rehospitalizations	1.602	.614	.204	2.607	.010
Number of specialists (besides pediatrician)	-.105	.355	-.031	-.297	.767
Number of medications on currently	-.439	.572	-.075	-.767	.444

Note. R^2 = .052 (p = .023) for Model 1; ΔR^2 = .124 (p = .012) for Model 2. The gray shading highlights significant findings.

TABLE 11

Table 3. Infant Health Indicators Predicting Family Burden

Model 1	**B**	**Std. Error**	**β**	**t**	***p***
Time since discharge	-.104	.031	-.262	-3.398	.001
Number of stressful life events	1.230	.878	.108	1.401	.163
Number of children	1.154	1.198	.072	.963	.337
Model 2					
Time since discharge	-.077	.027	-.195	-2.892	.004
Number of stressful life events	-.469	.727	-.041	-.645	.520
Number of children	-.301	.979	-.019	-.308	.759
Birth weight	.001	.001	.037	.500	.618
Length of stay in NICU	.137	.251	.052	.545	.587
ECMO during NICU stay	10.459	5.346	.121	1.956	.052
Number of medical devices during NICU	2.681	1.155	.159	2.321	.022
Number of medical devices at discharge	.957	1.198	.060	.799	.426
Additional diagnoses after discharge	3.092	2.649	.080	1.167	.245
Developmental disability	-1.730	2.726	-.044	-.635	.527
Number of current medical devices	2.383	2.772	.073	.860	.391
Number of rehospitalizations	2.025	1.132	.119	1.789	.076
Number of specialists (besides pediatrician)	1.914	.570	.296	3.360	.001
Number of medications on currently	1.833	.903	.167	2.030	.044

Note. $R^2 = .070$ ($p = .007$) for Model 1; $\Delta R^2 = .389$ ($p < .001$) for Model 2. The gray shading highlights significant findings.

TABLE 12

Table 4. Infant Health Indicators and Family Resources Predicting Parental Stress

Model 1	**B**	**Std. Error**	**t**	***p***	**Lower CI**	**Upper CI**
Family Resources	-.499	.171	-2.926	.004	-.871	-.162
Length of stay in NICU	.229	.286	.801	.424	-.336	.795
FR x LOS (interaction)	-.011	.017	-.636	.536	-.045	.023
Model 2						
Family Resources	-.502	.151	-3.316	.001	-.801	-.203
Additional Diagnoses	12.126	4.141	2.928	.004	3.947	20.305
FR x Add Diagnoses (Interaction)	-.300	.252	-1.188	.237	-.798	.199
Model 3						
Family Resources	-.523	.159	-3.298	.001	-.837	-.210
Number of rehospitalizations	-1.422	1.153	-1.234	.219	-3.698	.854
FR x Rehospitalizations (Interaction)	-.124	.095	-1.307	.193	-.311	.063

Note. $R^2 = .174$ ($p = .054$) for Model 1; $R^2 = .243$ ($p < .001$) for Model 2; $R^2 = .175$ ($p < .001$) for Model 3.

TABLE 13

Table 5. Infant Health Indicators and Family Resources Predicting Couple Functioning

Model 1	**B**	**Std. Error**	**t**	***p***	**Lower CI**	**Upper CI**
Family Resources	.204	.057	3.572	.001	.091	.316
Number of Medical Devices at Discharge	-1.504	.656	-2.291	.023	-2.799	-.208
FR x Med Devices Discharge (interaction)	.013	.063	.205	.838	-.111	.137
Model 2						
Family Resources	.208	.059	3.516	.001	.091	.324
Number of rehospitalizations	1.348	.543	2.484	.014	.277	2.419
FR x Rehospitalizations (Interaction)	.019	.044	.438	.662	-.068	.107

Note. R^2 = .212 (p < .001) for Model 1; R^2 = .204 (p < .001) for Model 2.

TABLE 14

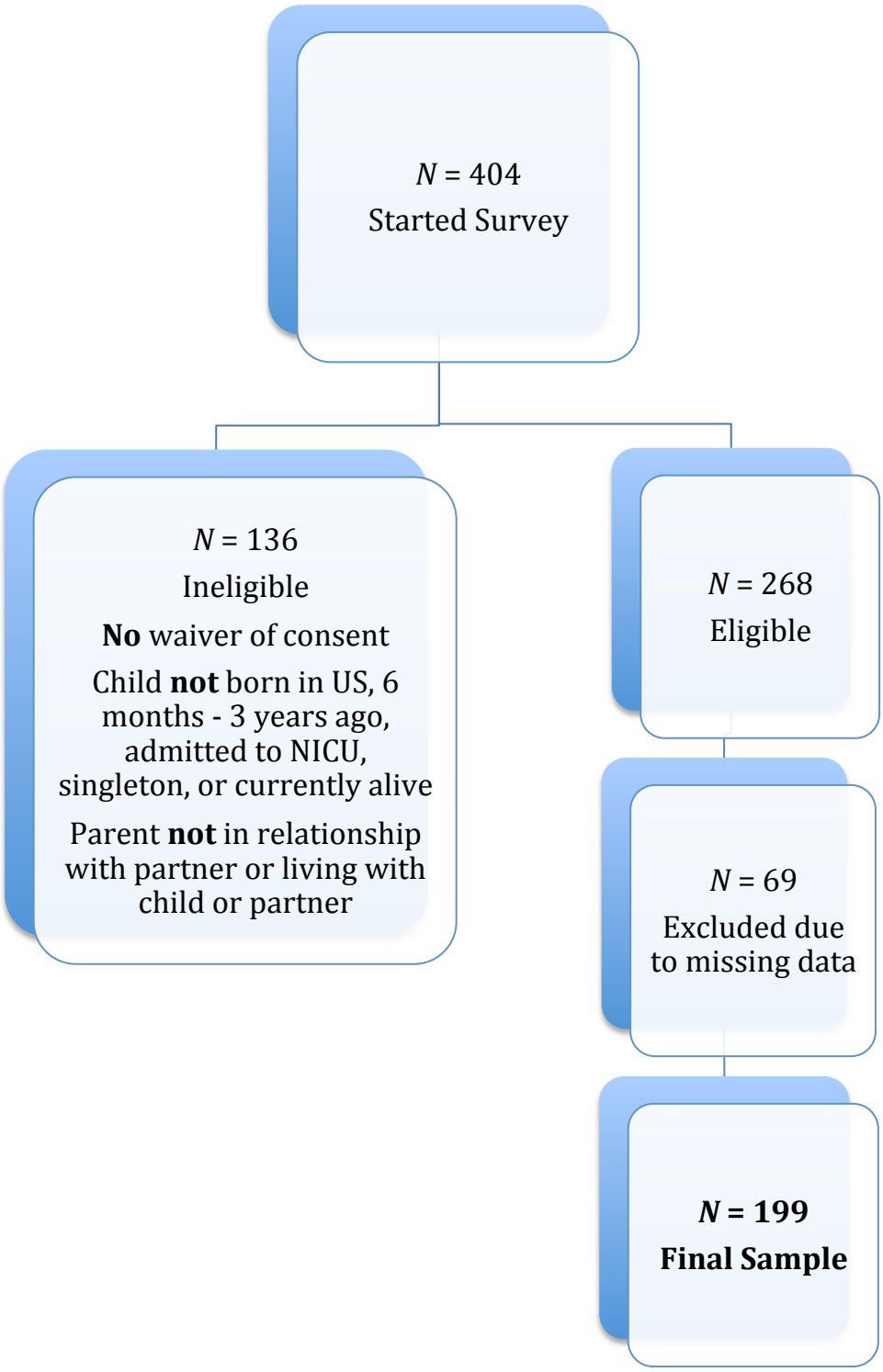
Table 6. Infant Health Indicators and Family Resources Predicting Family Burden

Model 1	**B**	**Std. Error**	**t**	***p***	**Lower CI**	**Upper CI**
Family Resources	-.231	.094	-2.468	.015	-.415	-.046
ECMO	13.474	17.357	.776	.439	-20.812	47.459
FR x ECMO (interaction)	-.050	.736	-.068	.946	-1.504	1.404
Model 2						
Family Resources	-.289	.121	-2.380	.019	-.529	-.049
Med Devices during NICU	5.342	1.167	4.577	.000	3.037	7.647
FR x NICU Med Devices (Interaction)	.039	.124	.316	.753	-.205	.283
Model 3						
Family Resources	-.189	.089	-2.112	.036	-.365	-.012
Number of specialists	3.495	.442	7.908	.000	2.623	4.368
FR x Specialists (Interaction)	.039	.028	1.406	.162	-.016	.094
Model 4						
Family Resources	-.209	.102	-2.04	.043	-.411	-.007
Number of Meds	4.948	1.042	4.751	.000	2.891	7.005
FR x Meds (Interaction)	.056	.077	.725	.470	-.096	.207

Note. $R^2 = .122$ ($p = .004$) for Model 1; $R^2 = .215$ ($p < .001$) for Model 2; $R^2 = .374$ ($p < .001$) for Model 3; $R^2 = .266$ ($p < .000$) for Model 4.

FIGURE 1

Figure 1. Participant Recruitment and Enrollment and Flow Information



APPENDIX A

Drexel University
Recruiting Volunteers for a Research Study

Research Title: NICU Infants, Parental Stress, Couple and Family Impact

Research Objectives:
The purpose of this study is to explore how families with neonatal intensive care unit (NICU) infants impact parental stress, couple and family functioning. We are interested how family resources may play a role these relationships. You will be asked to complete socio-demographic, infant health, parental stress, couple functioning and family functioning questionnaires to tell us about your experience having a NICU infant, so that we can better inform future intervention on risk and resilient factors for stress and family impact. It will take about up to 30 minutes to complete the survey. Your participation is completely anonymous.

Who Can Participate:

- Individuals who are biological mothers of infants admitted to a NICU 6 months – 3 years ago and their partners' or spouses'
- If you are currently in an intimate relationship with your partner from the NICU admission and have been cohabitating together and with the infant since NICU discharge.
- You must currently be 18 years old and reside in the United States.
- The infant must currently be alive and born a singleton.
- You also must be able to understand written English and have access to the Internet.

Compensation: You will not receive any compensation, but you may also enjoy providing your thoughts and opinions. In appreciation of your participation, the research team will donate $1 per participant to National Perinatal Association to thank you for sharing your experiences, and to benefit pregnant women, infants and families. At least 150 participants are expected to participate.

Contact Information:
If you have any questions about this study, you may contact the Principal Investigator, Dr. Pamela Geller, Ph.D., or the research coordinator, Victoria A. Grunberg, B.A. at infantresearchstudy@gmail.com or 215-553-7121.

If you would like to participate:
Please go to http://drexel.qualtrics.com/SE/?SID=SV_bBL3WQgREYmGp7L to take the survey. This research is approved by the Institutional Review Board at Drexel University and is being conducted by a researcher who is a member of Drexel University.

WAIVER OF CONSENT

Agreement to Participate:
You are being invited to participate in the study "NICU Infants, Parental Stress, Couple and Family Impact." This study is conducted by Victoria Grunberg, B. A. of the Drexel University Department of Psychology. To participate in the study, you must read this page and allow us to use your responses for research purposes.

Purpose:
The purpose of this study is to examine how a NICU infant impacts parental and family outcomes.

To be eligible for the study, you must be:

- Biological mother or her partner or spouse of an infant who was discharged from a NICU 6 months to 3 years ago
- In an intimate relationship with your partner from the NICU and cohabitating together and with the infant since discharge from the NICU
- At least 18 years old
- Live in the United States
- Infant must currently be alive
- Infant must have been born a singleton (e.g., not twin or triplet)
- Able to understand written English
- Have access to the Internet
- Agree to participate with this waiver of consent

Procedure:
If you agree to participate in the study, you will be asked questions about your age, relationship status, religion and religious practices, education, race and ethnicity, number of children, child's illness (if applicable), family impact, parenting stress, family resources, and intimate relationship functioning. It will take up to 30 minutes to complete the questionnaire.

Risks and Benefits:
Participating in this study poses no physical risks to you. There are no direct benefits to you from participating in this study, but you may also enjoy providing your thoughts and opinions. In appreciation of your participation, the research team will donate $1 per participant to National Perinatal Association to thank you for sharing your experiences, and to benefit pregnant women, infants and families. At least 150 participants are expected to participate.

Privacy and Confidentiality:
All of your responses will be anonymous and confidential. We are not asking any questions about your name or any information that could reveal your identity. Your responses will be stored in a secure, password-protected database. In any publication or presentation that results from this study, your responses will be combined with those of all of the other parents who have completed the survey.

Voluntary Nature of Participation:
Participation in this study is voluntary. You may choose not to participate, or you may stop participating after you begin responding to the survey questions. If you choose to stop participating after you begin the survey, simply close your browser window and your responses will not be saved. However, when you complete the survey and click the button labeled "Done," your responses will be saved in the database. Because we will not have any identifying information in your responses, we will not be able to remove your responses once you have submitted them. If you would like to have documentation that links you with this study, please contact the research team at vag47@drexel.edu.

Contact Information:
If you have any questions regarding this study, you may contact the Research Coordinator, Victoria Grunberg, at 215-553-7121 or infantresearchstudy@gmail.com. If you have any adverse reactions to the study, you may contact the Drexel University Office of Research Compliance at 215-762-3452. Referrals will also be provided at the end of the survey.

APPENDIX B

Screening Questions

Thank you for your interest in our survey! First, we need to ask you some questions to see if you are eligible to participate.

(1) Are you the parent of a child who was born in the United States?
    a. Yes
    b. No [IF NO, SEND TO END OF SURVEY]
        i. If yes, was your child born at least 6 months ago and less than 3 years ago?
            1. Yes
            2. No [IF NO, SEND TO END OF SURVEY]
                a. If yes, was your child previously admitted to a neonatal intensive care unit (NICU) in the United States?
                    i. Yes
                    ii. No [IF NO, SEND TO END OF SURVEY]

(2) What is your relationship to the NICU infant?
    a. Biological mother of NICU infant
    b. Biological father of NICU infant
    c. Not biologically related to NICU infant
        i. If so, are you:
            1. Spouse/Partner of biological mother of infant
            2. Spouse/Partner of biological father of infant
            3. Adopted mother
            4. Adopted father
            5. Grandmother
            6. Grandfather
            7. Other, please specify: _____

For this study, we are looking for participants who have been living with their NICU infant since the hospitalization AND who remain in a cohabitating relationship with the same partner present during the NICU hospitalization.

(3) Have you been living in the same home with your NICU infant since the NICU hospitalization?
    a. Yes
    b. No [IF NO, SEND TO END OF SURVEY]

(4) Have you been living in the same home with your spouse/partner since the NICU hospitalization?

a. Yes
b. No [IF NO, SEND TO END OF SURVEY]

(5) What is your current relationship status?
a. Married
b. Unmarried, but currently living with partner present during the NICU hospitalization
c. Unmarried, not living with partner present during the NICU hospitalization [SEND TO END OF SURVEY]
d. Separated from partner present during the NICU hospitalization [SEND TO END OF SURVEY]
e. Divorced from partner present during the NICU hospitalization [SEND TO END OF SURVEY]
f. Widowed from partner present during the NICU hospitalization [SEND TO END OF SURVEY]

(6) Was your NICU infant a singleton birth (e.g., not a twin or triplet)?
a. Yes
b. No [IF NO, SEND TO END OF SURVEY]

(7) Is your NICU child alive?
a. Yes
b. No [IF NO, SEND TO END OF SURVEY]

SOCIO-DEMOGRAPHICS QUESTIONNAIRE

Please answer the following questions to the best of your ability. Remember all of this information will be kept private and completely confidential. Although we hope that you answer every question, if there is something you do not wish to answer, you can skip it.

PART A: GENERAL INFORMATION

(1) Sex:
   a. Male
   b. Female
   c. Other (Please specify): _____

(2) How old are you (in years)?
   a. Please specify _____

(3) How do you best describe your race/ethnicity? (*Please circle all that apply*)
   a. African American/Black
   b. Asian/Pacific Islander
   c. Caucasian/White
   d. Latina/Latino/Hispanic
   e. Native American/Alaskan Native
   f. Other (Please specify): _____

(4) What is your current religious identity? If you identify with more than one option, please select the religion or practice with which you most identify at this time.
   a. Agnostic
   b. Atheist
   c. Buddhist
   d. Catholic
   e. Christian (includes all forms of Christianity that do not identify with Catholicism)
   f. Jewish
   g. Hindu
   h. Mormon
   i. Muslim
   j. Not affiliated, however, I am religious/spiritual
   k. No religious/spiritual identity
   l. Other

(5) How religious do you consider yourself to be?
   a. Not at all religious
   b. Somewhat religious
   c. Very religious

(6) What is the highest level of education you have completed?
   a. No formal education
   b. Some elementary school
   c. Some middle school
   d. Some high school
   e. High school graduate
   f. Some college
   g. 2-year college graduate or Associate's degree
   h. 4-year college graduate or Bachelor's degree
   i. Master's Degree
   j. MD/PhD/JD
   k. Other [Please specify]: _____

(7) What is your current employment status?
   a. Employed full time (35 hours/week or more)
   b. Employed full time (35 hours/week or more) but on maternity leave, FMLA, etc.
   c. Employed Part Time (less than 35 hours/week)
   d. Home maker/Stay at home
   e. Full Time Student
   f. Unemployed – Disability
   g. Unemployed – Looking for work
   h. Retired
   i. Other [Please specify]:_____

(8) What is your estimated approximate annual combined household income?
   a. Less than $25,000
   b. $25,000 - $49,999
   c. $50,000 - $74,999
   d. $75,000 - $99,999
   e. $100,000 - $124,999
   f. $125,001 - $150,000
   g. More than $150,000

(9) How many years have you and your spouse/partner been together in a committed relationship? (Please include years spent dating and married, if relevant).
   a. _____

(10) What is the sex of your partner?
   a. Male
   b. Female
   c. Other, please specify: _____

(11) In addition to yourself, is there anyone else who helps take care of the baby?
   a. Yes
   b. No

(12) Who of the following helps out with the care of the baby? [Please check all that apply, including yourself].

a. Biological mom
b. Biological dad
c. Non-biological father
d. Non-biological mother
e. Infant's grandparents
f. Infant's aunts or uncles
g. Infant's siblings
h. Nanny/baby sitter
i. Family friends
j. Professional day care
k. Other: please specify: _____

(13) How many days each week, on average, do each of the following provide primary care for the infant (e.g., If you and your partner care for the infant on Saturday, that would count as one day for both of you).
****ones that show up here will be the ones they select in question #11***

a. Biological mother: ____/7 days
b. Biological father: ____/7 days
c. Non-biological father: ___/7 days
d. Non-biological mother: ___/7 days
e. Infant's grandparents: ___/7days
f. Infant's aunts or uncles: ___/7 days
g. Infant's siblings: ___/7 days
h. Nanny/baby sitter: ___/7 days
i. Family friends: ____/7 days
j. Professional daycare: ___/7 days
k. Other: please specify: _____

(14) Approximately how long ago was your infant discharged from the NICU (years, months, or weeks or combination of these)? Note. Consider age of the child to help determine time since discharge. If readmitted, please count from last admission.

a. Years____/Months_____/Weeks: _____

(15) What is the sex of your infant?

a. Male
b. Female
c. Other (Please specify): _____

PART B. REPRODUCTIVE HISTORY

(1) How many children do you have? _____

(2) How many of your children are biologically related to you? _____

(3) How many of your children were admitted to a NICU following delivery?

_____

(4) Have you or your partner ever experienced a pregnancy loss (e.g., miscarriage, stillbirth, therapeutic abortion, or ectopic pregnancy)?

a. Yes
b. No

(5) If yes, how many pregnancy losses have you or your partner experienced?

_____

(6) Have you and your partner ever tried to become pregnant with the assistance of fertility treatments (including medications, intrauterine insemination, or in vitro fertilization)?

a. Yes
b. No

(7) If yes, was your NICU infant conceived via the assistance of fertility treatments?

a. Yes
b. No

(8) Were you aware that your infant(s) might enter the NICU before delivery?

a. Yes
b. No

(9) Are you or your partner currently pregnant?

a. Yes
b. No

PART C. PSYCHOLOGICAL HISTORY

(1) Have you ever suffered from or been diagnosed with any mental health problem (e.g., anxiety, depression, alcohol or drug abuse)?

a. Yes
b. No

(2) If yes please select all that apply:

a. Mental health problem prior to the pregnancy with the NICU infant
b. Mental health problem during the pregnancy with the NICU infant

c. Mental health problem while your infant was in the NICU
d. Mental health problem after your infant was discharged from the NICU

(3) Have you ever been in treatment for psychological or emotional distress?
a. Yes
b. No

(4) If yes, what type(s) of therapy have you tried in the past? [Please circle all that apply]
a. Individual therapy
b. Couple's therapy
c. Family therapy
d. Support groups/group therapy
e. Medication for psychological/emotional distress

(5) Are you currently in treatment for psychological or emotional distress?
a. Yes
b. No

(6) If yes, what type(s) of therapy are you currently using? [Please circle all that apply]
a. Individual therapy
b. Couple's therapy
c. Family therapy
d. Support groups/group therapy
e. Medication(s) for psychological/emotional distress
i. If yes, what medication(s)? _____

PART D: LIFE EVENTS

Listed below are events, which can bring about change in the lives of those who experience them. Please check the event(s) you have experienced since your child's birth.

Death

(1) □ Death of close family member (circle all that apply).
a. Mother
b. Father
c. Brother
d. Sister
e. Grandmother

f. Grandfather
a. Child (other than infant)
g. Other: Please specify: _____

(2) □ Death of a close friend

Health Issues/Injury

(2) □ Major personal illness or injury
(3) □ Serious illness or injury of close family member (circle all that apply):
a. Mother
b. Father
c. Brother
d. Sister
e. Grandmother
f. Grandfather
g. Spouse or partner
h. Child (other than infant)
i. Other (specify): _____
(4) □ Serious illness or injury of close friend

Finances and Job

(5) □ Major decrease in financial security (e.g., foreclosure on mortgage or loan)
(6) □ Lost your job (fired, quit, laid off, etc.)
(7) □ Spouse or partner lost their job

Legal Trouble

(8) □ Incarcerated
(9) □ Spouse or partner incarcerated
(10) □ Major law violation or legal trouble
(11) □ Major law violation or legal trouble for spouse or partner

INFANT HEALTH

Please answer the set of questions below. If you received a summary of your child's condition after leaving the NICU, you can use that information to help you answer the questions below.

Infant Past Health

(1) How many weeks gestation was your infant at birth? (Please round to the nearest week, e.g., 36 weeks)
   a. Weeks: ____

(2) Approximately, how long was your infant hospitalized in NICU(s) in total? Please report the amount of time in weeks (e.g., 1 month = 4 weeks, 6 months = 26 weeks, 1 year = 52 weeks).
   a. _____ weeks

(3) During NICU stay, was your infant on any of the following and for approximately how long (select all that apply and report weeks for each medical device, e.g., 2 weeks):
   a. None
   b. Oxygen
      i. Weeks: _____
   c. Ventilator support
      i. Weeks: _____
   d. Feeding tube
      i. Weeks: _____
   e. Tracheostomy
      i. Weeks: _____
   f. Other, please specify: _____

(4) Was your infant on extracorporeal membrane oxygenation (ECMO) during NICU stay?
   a. Yes
      i. If yes, for how long (report weeks, days or both):
         1. Weeks: _____; Days: _____
   b. No

(5) Birth weight [Please write in the weight of your infant in either pounds OR grams at the time of their birth]:
   a. Pounds: _____ Ounces: _____
   b. Grams: _____

(6) While in the NICU, was your infant fed by feeding tube?
   a. Yes
      i. If yes, for how many days: _____

b. No

(7) What was your infant's diagnosis/diagnoses during the NICU stay (please check all that apply and specify any other diagnoses in other if known):
   a. None
   b. Chronic lung disease (CLD)
   c. Respiratory distress syndrome (RDS)
   d. Apnea
   e. Pulmonary hypertension
   a. Seizures
   b. Brain bleeds
   c. Stroke
   d. Hypoxic-ischemic encephalopathy (HIE)
   e. Periventricular leukomalacia (PVL)
   f. Intraventricular hemorrhage (IVH)
   g. Heart defects
   h. Neural tube defects
   i. Down syndrome
   j. Abdominal wall defects
   f. Patent ductus arteriosus (PDA)
   g. Heart murmur
   h. Group B streptococcus (GBS)
   i. Listeriosis
   j. Late onset sepsis
   k. HIV
   l. Cytomegalovirus (CMV)
   m. Herpes
   n. Necrotizing enterocolitis (NEC)
   o. Cholestasis
   p. Reflux
   q. Condition requiring surgery
      i. Please specify the condition(s) and the surgical procedure(s) required: _____
   r. Other (any additional conditions not listed above): _____

Infant Current Health

(1) Upon discharge, was the infant on any of the following and for how long (select all that apply and report weeks on each medical device post-discharge even if still using medical device(s) Also, please indicate whether you are reporting weeks, days or both; e.g., 2 weeks):
   a. None
   b. Oxygen
      Weeks: _____ Currently in place? (y/n)
   c. Ventilator
      Weeks: _____ Currently in place? (y/n)

d. Cardiorespiratory monitor (i.e., used for apnea)
   Weeks: _____ Currently in place? (y/n)
e. Feeding tube: Circle: Oral gastric tube, Nasal gastric tube, or Gastrostomy tube
   Weeks: _____ Currently in place? (y/n)
f. Tracheostomy
   Weeks: _____ Currently in place? (y/n)
g. Ventricular Shunt
   Weeks: _____ Currently in place? (y/n)
h. Central Line
   Weeks: _____ Currently in place? (y/n)
i. Other, please specify: _____
   Weeks: _____ Currently in place? (y/n)

(2) Was your infant diagnosed with any additional conditions after being discharged from the NICU?
   a. No
   b. Please specify: _____

(3) Does your infant have a developmental disability or disabilities (e.g., developmental delay, intellectual impairment, cerebral palsy, visual/hearing impairment, autism, others)?
   a. No
   b. Yes
      i. Please specify: ____

(4) How many rehospitalizations did your infant require in the first year post-discharge from NICU (or if under 1 year since discharge, how many rehospitalizations since discharge)?
   a. No hospitalizations since NICU discharge
   b. Please specify: _____

(5) In addition to a pediatrician, which specialists did your infant see in the first year post-discharge from NICU (or if under 1 year since discharge, how many specialists seen since discharge)? [Check all that apply]
   a. None
   b. Pulmonologist
   c. Neurologists
   d. Cardiologist
   e. Endocrinologist
   f. Metabolic Specialty
   g. Genetics
   h. Occupational Therapy
   i. Physical Therapy
   j. Speech/Feeding Therapy
   k. Audiologist

l. Nutritionist
m. Ophthalmology
n. Cardiac surgery
o. Neurosurgery
p. General surgery
q. Craniofacial and Plastic Surgery
r. Ear, Nose, Throat Surgery
s. Orthopedics
t. Other: _____

(6) Is your child currently on any medication(s)?
   a. No
   b. If yes, how many medications is your child currently on? (List number and please check all that apply).
      i. ___ medication(s) (Enter number, e.g., 2 and circle all that apply or please specify)
         1. Pulmonary medications
         2. Anti-reflux medications
         3. Caffeine (e.g., for apnea of prematurity)
         4. Antibiotics
         5. Nutritional supplements (e.g., vitamin D)
         6. Diuretics
         7. Other: _____

FAMILY RESOURCES SCALE REVISED

This scale is designed to assess whether or not you and your family have adequate resources (time, money, energy, and so on) to meet the needs of your family as a whole as well as he needs of individual family members. For each items, please circle the response that best described how well the need is met on a consistent basis in your family (that is, month-in and month-out).

To what extent are the following resources adequate for you and your family?	Does not apply	Not at all Adequate	Seldom Adequate	Sometimes Adequate	Usually Adequate	Almost Always Adequate
Food for 2 meals a day	N/A	1	2	3	4	5
House or apartment	N/A	1	2	3	4	5
Enough clothes for your family	N/A	1	2	3	4	5
Heat for your house/apartment	N/A	1	2	3	4	5
Indoor plumbing/water	N/A	1	2	3	4	5
Good job for yourself or spouse/partner	N/A	1	2	3	4	5
Time to get enough sleep/rest	N/A	1	2	3	4	5
Furniture for your home or apartment	N/A	1	2	3	4	5
Time to be by yourself	N/A	1	2	3	4	5
Time for family to be together	N/A	1	2	3	4	5
Time to be with your child(ren)	N/A	1	2	3	4	5
Time to be with spouse/partner or close friend	N/A	1	2	3	4	5
Telephone or access to a phone	N/A	1	2	3	4	5
Someone to talk to	N/A	1	2	3	4	5
Time to socialize	N/A	1	2	3	4	5
Time to keep in shape and looking nice	N/A	1	2	3	4	5
Toys for your child(ren)	N/A	1	2	3	4	5
Money to buy things for yourself	N/A	1	2	3	4	5
Money for family entertainment	N/A	1	2	3	4	5
Money to save	N/A	1	2	3	4	5
Time and money for travel/vacation-	N/A	1	2	3	4	5

REVISED DYADIC ADJUSTMENT SCALE

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list.

	Always Agree	Almost Always Agree	Occasionally Agree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Religious matters	5	4	3	2	1	0
2. Demonstrations of affection	5	4	3	2	1	0
3. Making major decisions	5	4	3	2	1	0
4. Sex relations	5	4	3	2	1	0
5. Conventionality (correct or proper behavior)	5	4	3	2	1	0
6. Career decisions	5	4	3	2	1	0

	All the time	Most of the time	More often than not	Occasionally	Rarely	Never
7. How often do you discuss or have you considered divorce, separation, or terminating your relationship?	0	1	2	3	4	5
8. How often do you and your partner quarrel?	0	1	2	3	4	5
9. Do you ever regret that you married (or lived together)?	0	1	2	3	4	5
10. How often do you and your partner “get on each other’s nerves”?	0	1	2	3	4	5

	Everyday	Almost Everyday	Occasionally	Rarely	Never
11. Do you and your partner engage in outside interests together?	4	3	2	1	0

How often would you say the following events occur between you and your partner?

	Never	Less than once a month	Once or twice a month	Once or twice a week	Once a day	More often
12. Have a stimulating exchange of ideas	0	1	2	3	4	5
13. Work together on a project	0	1	2	3	4	5
14. Calmly discuss something	0	1	2	3	4	5

PARENTING STRESS INDEX – SHORT FORM

The questions below will ask you to identify the sources and different types of stress that every parent can experience. Please indicate the degree to which you agree or disagree with each of the following statements.

SA = Strong Agree A = Agree NS = Not Sure
D = Disagree SD = Strongly Disagree

(1) I often have the feeling that I cannot handle things very well
(2) I find myself giving up more of my life to meet my children's needs than I ever expected.
(3) I feel trapped by my responsibilities as a parent
(4) Since having this child, I have been unable to do new and different things
(5) Since having a child, I feel that I am almost never able to do things that I like to do
(6) I am unhappy with the last purchase of clothing I made for myself
(7) There are quite a few things that bother me about my life
(8) Having a child has caused more problems that I expected in my relationship with my spouse/parenting partner
(9) I feel alone and without friends
(10) When I go to a party, I usually expect not to enjoy myself
(11) I am not as interested in people as I used to be
(12) I don't enjoy things as I used to
(13) My child rarely does things for me that make me feel good
(14) When I do things for my child, I get the feeling that my efforts are not appreciated very much
(15) My child smiles at me much less than I expected
(16) Sometimes I feel my child doesn't like me and doesn't want to be close to me
(17) My child is very emotional and gets upset easily
(18) My child doesn't seem to learn as quickly as most children
(19) My child doesn't seem to smile as much as most children
(20) My child is not able to do as much as I expected
(21) It takes a long time and it is very hard for my child to get used to new things
(22) I feel that I am [Choose a response from the choices below]
    1. A very good parent
    2. A better-than-average parent
    3. An average parent
    4. A person who has some trouble being a parent
    5. Not very good at being a parent
(23) I expected to have closer and warmer feelings for my child that I do, and this bothers me
(24) Sometimes my child does things that bother me just to be mean
(25) My child seems to cry or fuss more often than most children
(26) My child generally wakes up in a bad mood
(27) I feel that my child is very moody and easily upset
(28) Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house
(29) My child reacts very strongly when something happens that my child doesn't like
(30) When playing, my child doesn't often giggle or laugh
(31) My child's sleeping or eating schedule was much harder to establish than I expected
(32) I have found that getting my child to do something or stop doing something is: [choose a response from the choices below]…
    1. Much harder than I expected

2. Somewhat harder than I expected
3. About as hard as I expected
4. Somewhat easier than I expected
5. Much easier than I expected

(33) Think carefully and count the number of things which your child does that bothers you. For example, dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. [choose a response from the choices below]…

1. 1-3
2. 4-5
3. 6-7
4. 8-9
5. 10+

(34) There are some things my child does that really bother me a lot

(35) My child's behavior is more of a problem that I expected

(36) My child makes more demands on me than most children

IMPACT ON FAMILY SCALE REVISED

Below are some statements that people have made about living with an ill child. For each statement, please report whether at the present time you would strong agree, agree, disagree, or strongly disagree with the statement. For illness specific items, if your child does not have any current medical issues, please mark *does not apply*.

Strongly Agree = 1; Agree = 2; Disagree = 3; Strongly Disagree = 4; Does not apply = 5

(1) Fatigue is a problem for me because of my child's illness.
(2) We see family and friends less because of the illness.
(3) Sometimes we have to change plans about going out at the last minute because of my child's state.
(4) We have little desire to go out because of my child's illness.
(5) I don't have much time left over for other family members after caring for my child.
(6) I live from day to day and don't plan for the future.
(7) It is hard to find a reliable person to take care of my child.
(8) Our family gives up things because of my child's illness.
(9) Nobody understands the burden I carry.
(10) Because of the illness, we are not able to travel out of the city.
(11) Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable
(12) People in the neighborhood treat us specially because of my child's illness.
(13) Traveling to the hospital is a strain on me.
(14) I think about not having more children because of the illness.
(15) Sometimes I wonder whether my child should be treated "specially" or the same as a normal child.

FOLLOW-UP QUESTION

(1) How did you access/hear about this survey? Through a post on or flyer at…
    a. the study's Facebook page
    b. the study's Craigslist page
    c. a person's Facebook page
    d. a support group website
    e. pediatrician's office
    f. medical professional's office
    g. developmental follow-up clinic
    h. Other: [Please Specify] _____
    i.

APPENDIX C

All participants in the study will receive a list of mental health referrals and information about NICU parent support groups.

Mental Health Referrals

To find psychological support:

- Call the number on the back of your insurance card and request a list of behavioral health providers in your area
- Contact NICU social workers to request a referral in your area
- Utilize the following web resources to find a psychologist or therapist in your area:
    - American Psychological Association Psychologist Locator: http://locator.apa.org/
    - Association for Behavioral and Cognitive Therapies Find a Therapist Service: http://www.abct.org/Members/?m=FindTherapist&fa=FT_Form&nolm=1

Parenting resources and groups

To find NICU family support groups:

- March of Dimes: http://www.marchofdimes.org/mission/march-of-dimes-services-in-the-nicu.aspx#
- Graham's Foundation: http://grahamsfoundation.org/
- Hand to Hold: http://handtohold.org/
- Together Let's Cope: http://www.stjohnprovidence.org/tlc/

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